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**Calling NHS 24: Exploring caller
decision making and help seeking
behaviour within the context of
out-of-hours health care provision**

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**Doctor of Philosophy
University of Edinburgh
2015**

Declaration

I hereby declare that:

- This thesis has been composed solely by myself
- The work presented within this thesis is my own
- This work has not been submitted for any other degree or professional qualification.

Emma Doyle, March 2015

Abstract

Decisions about where and when to seek advice about illness are known to be complex and are often bound up with issues of risk, responsibility and legitimacy. They can be particularly difficult in situations where the meaning and severity of symptoms is unclear. In deciding whether or not to seek help, people must negotiate the tension between using health services in ways that are considered appropriate, while not taking risks with their health or that of the person they are caring for. This thesis explores how individuals account for a specific decision to call NHS 24 about symptoms in themselves or someone they were caring for and how that decision fits within their use of health services more generally. Building on what is already known about help-seeking behaviour, it seeks to understand how people interpret symptoms as needing or not needing attention and what is understood by appropriate help-seeking in the context of out-of-hours care.

There have been significant changes to the way that out-of-hours health care is provided in Scotland. An increase in routes into care means that people must negotiate a complex health system when seeking help. At the same time, pressure on resources has created an imperative to ensure that health care is used in the most efficient way possible. NHS 24 is primarily an out-of hours triage service providing assessment and, where necessary, referral to other services. At its inception, NHS 24 was presented as being designed to simplify access to health care by acting as a 'gateway' to the NHS in Scotland. However, increasing demand has led to attempts to limit use of NHS 24, in the out-of-hours period, to situations where symptoms are considered to be too urgent to wait for a GP appointment. NHS 24 can now be understood as one of a number of different points of access to health care that people must choose between; this requires individuals to engage in a process of categorising their symptoms according to urgency as a way of ensuring that their call is considered appropriate.

The thesis draws on data from 30 in-depth semi-structured interviews with people who had called NHS 24 in the out-of-hours period. The symptoms the participants had called about were generally, though not universally, what might be classed as

minor symptoms. Most of the interviewees were given self-care advice rather than referral for a face-to-face consultation. The interviews focussed on a specific contact with NHS 24 but aimed to situate the call in the context of the interviewee's understanding of NHS 24, as well as their illness behaviour and use of health services more generally. The analysis suggests that people's understandings of NHS 24 are not straightforward and that this can cause some confusion and even anxiety for callers. Interviewees' accounts emphasise uncertainty about the severity of symptoms, a sense of worry that symptoms may be indicative of a serious problem, and the inadequacy of their own knowledge in the face of potential risks. In talking about their reasons for calling NHS 24, they describe seeking, and obtaining, reassurance that they were 'doing the right thing'. Although they generally construct themselves as healthy individuals, confident in their ability to self-care, and as responsible users of health services, people spoke frequently about their reliance on expert clinical knowledge in decision-making. The analysis suggests that when explored in the context of individual circumstances and the broader social context, calling NHS 24 about minor symptoms can be constructed as a rational and responsible act.

While this thesis is primarily an exploration of the accounts of individuals who have called NHS 24, the accounts are situated within the broader social and structural context in which those individuals make their decisions about symptoms and help-seeking. A social constructionist perspective sees illness behaviour as shaped by the social structures and values of a society and by the health system operating in that society. Equally, the health system is shaped by individual actors, who define it by how they choose to use it and what they expect it to deliver. This thesis argues that understandings of risk and individual responsibility, as well as a policy emphasis on self-surveillance and self-care, shape the decisions made by individuals as well as the discourses available to them to account for those decisions. Drawing on theories of medicalisation and lay re-skilling, the thesis also aims to develop an understanding of the space that NHS 24 occupies in Kleinman's (1980) model of the health system, and whether the service might best be conceptualised as 'legitimation' or 'colonisation' of the popular sector (Stevenson et al. 2003)

Lay summary

When people are ill they have to decide whether or not to seek medical attention. Many different factors can affect this decision and it can be particularly difficult to decide what to do if you are not sure how serious the symptoms might be. People may worry about wasting a doctor or nurse's time, but they have to weigh this against the risk that someone is seriously ill and needs to be seen. In this study, 30 people who had called NHS 24, in the evening or at the weekend, about symptoms that turned out to be suitable for self-care at home, were asked about why they decided to call NHS 24 and their experience of using the service. NHS 24 is a telephone service that offers assessment and, where necessary, referral to other health services. It is designed to help people to access the right service to meet their needs, but it is only supposed to be used for urgent symptoms in the out-of-hours period. This means that people have to decide if their symptoms are urgent enough before calling NHS 24 to avoid being seen as wasting time.

This study looks at how and why people decided to call NHS 24 and what sorts of things they usually do when ill or looking after someone who is ill. The study shows that people have different understandings of the purpose of NHS 24. Some people are not sure what types of illness the service is for and this can make them anxious about whether or not to call. People find it very difficult to know how serious symptoms are and worry that even something that seems minor could be a sign of something worse. One reason for calling NHS 24 is to get reassurance that they are doing the right thing and that there is nothing seriously wrong. People talked about the limits to their knowledge about illness and the importance of getting expert advice. This thesis considers the social context in which people make decisions about illness, for example awareness of risks and a policy emphasis on encouraging self-care. It aims to help us to understand NHS 24's role in the health care system in Scotland.

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1. Introduction

Rising demand for health care has become a ‘headline issue’ in the UK (Klein 2010) and, in the policy context at least, this is considered to be problematic, particularly when associated with rising costs. As a result, various demand management strategies have been deployed, including the rationing of services and attempts to modify patient behaviour (Rogers et al. 1999). At the same time, what has been described as a neoliberal agenda centred on ideas of individual responsibility, choice and active citizenship (Petersen and Lupton 1996) has created an increasing expectation that individuals should keep themselves healthy and, when ill, should use health services in the most resource-efficient way possible. This has led to a policy emphasis on self-care and encouraging ‘appropriate’ use of health services, accompanied by campaigns such as ‘Choose Well’ (in England and Wales) and ‘Know Who To Turn To’ (in Scotland). A further development aimed to manage demand by offering ‘more graduated access to healthcare’ (Pencheon 1998: 215) has been the introduction of 24-hour telephone advice and assessment via NHS Direct (now NHS 111) and NHS 24.

Decisions about health and illness are known to be complex and are bound up with issues of risk, responsibility and legitimacy (Zola 1972; Dingwall 1976; Cornwell 1984; Lupton 2012). They can be particularly difficult in situations where the meaning and severity of symptoms is difficult to interpret (Locker 1981; Jutel 2011a). Everyday illnesses can usually be managed with self-care and it has been well established that the majority of symptoms do not result in any action or are managed in the community (Hannay 1979; Elliot et al. 2011). At the other extreme, serious injuries or obviously life-threatening symptoms will evidently require an emergency response. However, when symptoms don’t fall clearly into either of these categories, decisions must be made about whether or not they are serious, whether or not to seek medical attention and, if medical attention is required, how urgently and from what service. These are complex decisions, influenced by a broad range of factors (Hopton et al. 1996). In making these decisions, people must negotiate the tension between using health services ‘appropriately’ to avoid being labelled a ‘time-waster’ or ‘over-anxious’ and at the same time not taking risks with their health or

that of the person they are caring for. Negotiating this tension can be problematic, particularly where people feel they do not have adequate knowledge or experience to assess the severity of symptoms themselves. Telephone advice, assessment and triage offers a solution, potentially enabling people to manage risks and share responsibility with someone who has more specialised knowledge.

In Scotland, as elsewhere, rising demand for out-of-hours health care has been framed as a particular problem, although this is difficult to measure accurately due to a lack of suitable and comparable data (Salisbury 2000; Godden et al. 2011). Nevertheless, the idea that demand is rising and that the pattern of demand is changing has come to inform the planning of services (NHS 24 2011). Over the past decade, there have been significant changes to the way that out-of-hours care is provided in Scotland, with an increase in routes into care leading to a more complex health system for people to negotiate when seeking help (Audit Scotland 2007; Salisbury and Bell 2010; Godden et al. 2011). Although there is no evidence that these changes have reduced overall demand for unscheduled care (Audit Scotland 2010), it is possible that changes to the organisation of care could be influencing illness behaviour (Mark and Shepherd 2004). One of the most significant changes has been the introduction of NHS 24.

1.1 NHS 24

NHS 24 is a special health board that was established in 2001 and has been operational since 2002. It describes itself as ‘Scotland’s telehealth and telecare organisation’ and it aims to help people to ‘get the right care, from the right people, at the right time’ (www.NHS24.com/aboutus). When it was first launched, it was designed to offer health information and advice to people who did not need to be seen face-to-face and to enhance the co-ordination of out-of-hours health and care services. However, in 2004, the introduction of a new GP contract led to NHS 24 becoming the first point of contact for all out-of-hours medical care, resulting in a new role for the organisation and significant challenges in meeting increased demand. A more detailed account of its establishment, aims and early operation is provided in chapter 2.

The main service offered by NHS 24 is the unscheduled care telephone service, accessed via the Freephone number 111. This service provides assessment, advice and, where necessary, referral to local health services or emergency care. It receives around 1.5 million calls per year, 89 per cent of which are in the out-of-hours period (NHS 24 2013). NHS 24 now has 4 main contact centres located in Aberdeen, South Queensferry (Edinburgh), Clydebank and Cardonald, as well as local satellite centres in all other health board areas. Calls are first routed to the centre most local to the caller but can be answered in any centre to ensure the quickest possible response.

When someone calls NHS 24, they hear a recorded message explaining that all calls are recorded and that the service is for patients who require urgent medical attention that cannot wait. Callers are advised to call 999 if their condition is an emergency. They are then offered a list of options to choose from, including to listen to information on the treatment of colds and sore throat, or diarrhoea and vomiting of less than 6 hours' duration; to be put through to a dental adviser; or, if urgent medical attention is required, to wait for their call to be answered.

Calls are answered by a call handler, who asks for details including the reason for the call, the patient's name, date of birth, home address and telephone number and the patient's GP details. The call handler then asks a series of questions to ascertain the nature of the symptoms and uses computer algorithms to determine the level of urgency of the call, in a process known as call streaming. Based on the outcome of the call streaming, the call handler will then transfer the call to the appropriate adviser or, in some very limited circumstances, they may refer the patient to another service or they may offer self-care advice and close the call.

If the call is transferred to an adviser (e.g. a nurse, dental nurse, mental health nurse or pharmacist), the patient will be assessed, again with the assistance of computer algorithms if required, to determine the best route to care. The adviser may give self-care advice or they may direct the patient to another service such as a pharmacy, their own GP, a primary care emergency centre (PCEC) or an emergency department. If necessary, the nurse can arrange an appointment at a PCEC, arrange for a home visit, or arrange an ambulance. When a patient is referred on to another service, a clinical summary of their call is sent ahead and a record is also sent, with the patient's consent, to their GP.

At busy times, if an adviser is unavailable, calls that are not streamed as serious and urgent may be placed in a queue for call-back. The queue is constantly monitored by a clinician who looks at each call within 10 minutes of it being placed in the queue to determine if it can safely wait or if it needs to be reprioritised or dealt with immediately. Each call is then given a priority number from 1 to 3. The queue is also monitored to identify callers who have called more than once about the same problem and especially those whose symptoms have got worse, as these calls may need an immediate response.

Alongside the unscheduled care service, NHS 24 offers a range of other online and telephone services which include the Health Information Service (by phone and via the NHS Inform website); Care Information Scotland; Smokeline; a hepatitis helpline; a waiting times helpline; a patient reminder service; a musculoskeletal triage service for 3 health board areas; Living Life (Cognitive Behavioural Therapy); Breathing Space (for people experiencing depression or anxiety); and access to resources via digital television and apps. The Scottish Centre for Telehealth and Telecare has been part of NHS 24 since 2010 and plays a lead role in the development of telehealthcare services in Scotland.

A note on NHS Direct and NHS 111

I refer frequently in this thesis to research concerning the now defunct service NHS Direct. While research on NHS 24 is extremely limited, there is a far more extensive body of work on NHS Direct and, although there are some differences between the services, for the purposes of this research they are similar enough for many NHS Direct-based findings to be highly relevant.

NHS Direct was a nurse-led telephone advice and information service which operated from the late 1990s until 2014. It originally operated in both England and Wales, but NHS Direct Wales became a separate entity in 2001 and has continued to operate since the dissolution of NHS Direct. The aims of NHS Direct were similar to those of NHS 24; however, there were some important differences in its implementation, most notably that it was franchised rather than being a national service and that it was less integrated with other health services (Heaney et al. 2005).

A new single-number helpline, NHS 111, was trialled in 2010 and launched in England in 2013, completing its roll-out in early 2014. The key differences between it and NHS Direct are that NHS 111 is free to call; calls are answered and assessed immediately by a non-clinical call handler; there is more emphasis on direction to other services than on reassurance and self-care advice; only some calls are assessed by a nurse with most being triaged by call handlers; and the assessment system is more integrated with other services (Turner et al. 2013). NHS Direct had initially planned to continue as one of several providers of the NHS 111 service, winning 11 of 46 operating contracts (Triggle 2013a) but it withdrew from these contracts amidst financial difficulties and was dissolved in March 2014. While NHS 24 now also uses the free 111 number, the service in Scotland retains its separate identity and operational distinctiveness.

1.2 Background to the research

This thesis arose from an opportunity to carry out a doctoral research project supported by NHS 24 through an ESRC CASE studentship. An initial plan to research illness behaviour amongst callers was developed by a Co-director at the Centre for Research on Families and Relationships and the Medical Director of NHS 24. However, the specific aims of the research were not prescriptive and they were developed throughout the course of the project.

In spite of an extensive body of existing research on illness behaviour, there have been calls to develop a better understanding of the decision-making process that people go through when determining when, where and how to seek health care, particularly out-of-hours (BMA Scotland 2010; 2012). In recognition of this, I chose to focus the attention of this research on the out-of-hours period (i.e. from 6pm to 8am on weekdays and all day at weekends and on public holidays). I was also interested in the apparent redefinition of NHS 24 from a general advice line to being specifically for ‘urgent’ symptoms in the out-of-hours period and what this might mean for the people who use it. Therefore I decided to focus on situations where there may be some ambiguity about the severity of symptoms. I made the assumption that if people called NHS 24 about a symptom or illness which, on assessment, was

found to be suitable for self-care, it was likely to have been because they were unsure about the level of care needed. As a result, I aimed to interview participants who had called about what might be classed as minor symptoms; although this raised questions about the interpretation of symptoms as ‘minor’, ‘urgent’ or ‘emergency’ which I engage with in the thesis.

While this thesis is primarily an exploration of the accounts of individuals who have called NHS 24, the accounts are situated within the broader social and structural context in which those individuals make their decisions about symptoms and help-seeking. I have taken a social constructionist perspective (Berger and Luckman 1967) which sees illness behaviour as shaped by the social structures and values of a society and by the health system operating in that society. Equally, I see the health system as shaped by individual actors who define it by how they choose to use it and what they expect it to deliver. I argue that understandings of risk and individual responsibility, as well as a policy emphasis on self-surveillance and self-care, shape the decisions made by individuals as well as the discourses available to them to account for those decisions.

Existing research on NHS 24 is extremely limited and largely draws on health professional perspectives or quantitative data (Heaney et al. 2005; Haddow et al. 2007; O’Cathain et al. 2007; Roberts et al. 2009; Cook et al. 2010). This thesis is the first in-depth exploration of caller perspectives (other than an MSc thesis, Ireland 2012) and, as far as I am aware, the first qualitative study to explore help-seeking decisions out-of-hours in Scotland since the introduction of NHS 24. I build on the small body of qualitative work about callers to NHS Direct (Goode et al. 2004a; Goode et al. 2004b; O’Cathain et al. 2005; Rubin et al. 2010) and engage with the themes of risk, responsibility and reassurance present in that literature. This thesis adds an insight into understandings and expectations of NHS 24, how ‘appropriate’ help-seeking is constructed in the context of out-of-hours care and a development of the concept of risk in the context of decision-making about acute symptoms.

1.3 Aims of the research

In this research, I aim to understand the decision-making process that people go through when deciding, in the out-of-hours period, whether or not to seek advice about symptoms which they cannot easily dismiss as minor but which do not obviously require emergency attention. In particular, I seek to understand how people interpret symptoms as needing or not needing attention, how they determine the most ‘appropriate’ route to care, and what is understood by appropriate help-seeking in the context of calling NHS 24. I ask how realistic it is to expect people to ‘know who to turn to’ and to categorise their symptoms according to urgency in the way that service provision increasingly seems to require.

I aim to explore the expectations of individual callers when calling NHS 24, how they understand the service and its purpose and why they called NHS 24 rather than caring for themselves or using other routes to health care. An underlying premise is that changes to the provision of out-of-hours care may be transforming aspects of illness behaviour as options for patients increase and they interact in different ways with service providers.

Drawing on theories of medicalisation and lay re-skilling, I aim to develop an understanding of the space that NHS 24 occupies in Kleinman’s (1980) model of the health system and what this means for how people understand and experience using the service. I also aim to explore how people’s use of NHS 24 might fit in to lay understandings of risk and responsibility in relation to illness and what it means to ‘take responsibility’ in the context of decision-making about symptoms, paying attention to the importance of reassurance and expert knowledge.

1.4 Outline of the thesis

In this brief introductory chapter I have presented the background to this study, introduced the context in which the research has been carried out and described the aims of the research. The content of the remaining chapters is outlined below.

Chapter 2 begins by outlining the case for a consideration of illness behaviour and health service use in the context of the whole health care system. I introduce

Kleinman's (1980) concepts of the popular and professional sectors of care and draw on theories of medicalisation and lay re-skilling to show how the boundaries between these sectors are both shifting and permeable. I then set out the policy and cultural context in which NHS 24 was introduced and currently operates. I briefly explore relevant literature on telephone consulting in primary care, including the very limited existing literature on NHS 24 and the slightly more extensive literature on NHS Direct. The chapter then focusses on the concepts of illness behaviour and help-seeking, exploring in particular ideas about 'appropriate' help-seeking.

Chapter 3 outlines the methods used in the research design, data collection and analysis. The sample of interviewees is introduced. Ethical considerations are explored, and attention is paid to the role of the researcher in the process of research.

Chapter 4 begins to introduce my empirical data and presents an analysis which suggests that staff and service users' understandings of NHS 24 are not straightforward. This allows for some flexibility in the construction of appropriate service use, but it may also cause confusion and even anxiety for callers. I suggest that this analysis of people's understandings of NHS 24 is fundamental to further exploration of how and why they use the service.

Chapter 5 draws on accounts in which interviewees talk about their worries that seemingly minor symptoms could be indicative of, or could turn into, more serious conditions. I explore the idea that a sense of risk underpins many decisions to contact a health service about minor symptoms and that this risk is one which is difficult to assess, particularly in the absence of relevant expertise. I present data which suggests that, for almost all interviewees, the decision to call NHS 24 involved a need or desire for reassurance. For some interviewees seeking reassurance was the explicitly stated purpose of their call. I show how calling NHS 24 can be experienced as reassuring, or not, paying attention to the impact of the call structure and the act of questioning.

Chapter 6 considers the extent to which people had taken measures to care for themselves or their children before contacting NHS 24. I explore interviewees'

attitudes to self-care more generally and, specifically, to self-medication and medicating children. I highlight again how difficult it is for people to assess symptoms and know the ‘right’ thing to do and I suggest that while deciding to seek professional advice could be seen as abdicating individual responsibility for health, it can also be seen as taking responsibility.

Chapter 7 explores the extent to which a decline in social support and access to lay knowledge is likely to account for increased demand for professional health care. I show that most people in this study are embedded in close family networks and that those who live some distance from family and friends use communication technology to remain in regular contact. Many interviewees described engaging in lay consultations, although these were likely to result in referral to the professional sector. People also described drawing on a range of other sources of knowledge and information in making decisions about symptoms and help-seeking; however, these accounts were complex and sometimes contradictory, as most interviewees constructed themselves as mistrustful of lay knowledge even though they often incorporated it into their decisions. Interviewees frequently spoke about the decision to call NHS 24 being due to a desire to speak to a professional and this chapter suggests that it is the increased accessibility of professional knowledge via services such as NHS 24, rather than a significant decline in the accessibility of lay knowledge, that leads people to seek help from the professional sector.

Chapter 8 draws my findings together in a discussion of how the participants understand and use NHS 24 and how this may be linked to health policies and broader social trends. While acknowledging the limitations of this study, I suggest some implications for policy and NHS 24 practice and suggest areas for further research and theoretical development.

2. Literature review

This chapter introduces the literature and theoretical concepts I will draw on in this thesis. It is a selective review which includes work from across the disciplines of sociology, anthropology, social policy and health services research. This reflects my cross-cutting interests and belief that each of these perspectives has something useful to offer to the present study. I searched and read widely across several areas of theoretical interest and used a ‘snowball’ technique to identify further books, papers or ideas of potential relevance. Much of the literature was identified subsequent to data analysis, once key themes had been identified. Some of the themes touched on in this literature review will be covered in more depth in later chapters and in the discussion. Parts of this chapter draw on a core body of sociological work, some of which was written quite some time ago; however, I aim to show its continued relevance to the contemporary context.

The chapter begins with a discussion of the need to consider illness behaviour in the context of the health care system and the organisations that provide care. Existing research on NHS 24 has been largely oriented to the organisational perspective and links with illness behaviour and help-seeking have not been previously explored. I introduce Kleinman’s (1980) model as a useful heuristic device for understanding what is meant by a health care system, focusing in particular on what Kleinman describes as the popular and professional sectors of health care. I draw on theories of medicalisation and lay re-skilling to show how the boundaries between these sectors are both shifting and permeable and I suggest that there are interesting questions to be asked about where a service such as that provided by NHS 24 might best be located in Kleinman’s model.

The second section outlines the policy context in which NHS 24 was established and now operates. This is important because policy aimed to manage demand and encourage the appropriate use of health services often ignores the impact of organisational change and professional behaviour on how people actually use services (Rogers et al. 1999). I then give an account of the implementation of NHS 24 and highlight the early challenges that were faced by the organisation. This

provides valuable contextual information which helps us to understand how NHS 24 has been, and continues to be, perceived by those who work in and use the service.

In the final section of the chapter, I focus attention on the concepts of illness behaviour and help-seeking. I discuss how people respond to the presence of symptoms and, specifically, how they might differentiate between minor and serious symptoms and the necessity for emergency or routine care. I attend here to ideas about what might be meant by ‘appropriate’ help-seeking and how ‘appropriateness’ is constructed in different contexts. I suggest that appropriate use of health services requires people to categorise their symptoms according to criteria, such as ‘urgency’, that are contingent and ill-defined, and that this is made more difficult in the context of heightened awareness of risk.

2.1 Organisations and health care systems

There is an argument that medical sociology has often tended to focus on macro-level issues such as the broad social determinants of health and illness or on micro-level issues such as individual doctor-patient relationships but that there has been less of a focus on the level of policy and organisational processes (Hunter 1990). The history of organisational research in medical sociology has been outlined in a review by Davies (2003) who argues that there is a need for sociologists of health and illness to re-engage with organisations and to acknowledge the impact of organisational structures on both policy and society. Davies calls for attention to be paid to understanding patient journeys, particularly in light of new organisational arrangements and policy shifts which, she suggests, coincide with and contribute to the destabilisation of traditional medical authority. One of the areas in which Davies suggests that theory could usefully be developed is in relation to the expansion of health care beyond the walls of the hospital and the implications of new technologies for both professional identities and patient journeys. Since Davies’ review, there have been some attempts to bridge the gaps she identified (Currie et al. 2012) but this remains an area in which there is room for further work.

While the research presented in this thesis does not go as far as meeting Davies’ call to make organisations the subject of the investigation rather than the backdrop to the

analysis, I have taken heed of her argument that ‘the realignments between health care professions and between professions, patients and the public [...] merit particular attention’ (Davies 2003: 180) and that ‘sociology needs to take seriously the politics of NHS “modernisation” and the aspirations which lie behind it’ (2003: 183). The approach I have taken is more in line with that advocated by May (2007) who argues that sociological consideration of the clinical encounter continues to be dominated by a ‘Parsonian paradigm’ of individual, proximal relations between doctors and patients, detached from the contexts in which these encounters take place. May (2007: 40) suggests that while these proximal relations remain important, changes to the structure and organisation of medical work, especially in general practice, are already having an impact, for example in the ‘collapse of longitudinal relationships between patients and doctors’. Rather than calling, as Davies (2003) and Griffiths (2003) have done, for attention to be paid to the organisations themselves, May (2007: 41) draws attention to the need to understand the clinical encounter not just as a privatised, interpersonal interaction but as ‘one part of an assemblage of complex organisational, institutional and disciplinary resources and practices’.

In fact, organisational issues have been remarkably well attended to in relation to NHS 24 and NHS Direct, though predominantly through the lens of service evaluation rather than through a sociological one. The majority of published work relating to both of these services is focussed at the organisational level, which is unsurprising given their intended role in managing demand for other unscheduled care services. In the case of NHS 24, the very limited research which has been published draws on health professional perspectives and service-level data, mostly collected during the evaluation of the implementation of the service (Heaney et al. 2005). Two papers, based on policy and professional stakeholder interviews, emphasise the heterogeneity of pre-existing service delivery and the difficulties the new organisation faced in integrating with partner organisations (Haddow et al. 2007), particularly in remote and rural communities (Roberts et al. 2009); and one further paper from the same evaluation uses quantitative data to explore NHS 24 nurses’ attitudes to risk (O’Cathain et al. 2007). The only published research on NHS

24 which was not part of the evaluation of its implementation considers doctors' views on the appropriateness of NHS 24 referrals to an emergency department (Cook et al. 2010). None of these papers make links between organisational change and the ways in which people use health services and none of them explore the perspectives of callers.

There has been far more research on NHS Direct and again much of the focus has been on understanding its impact on other services such as A&E, ambulance and out-of-hours GP co-operatives (Munro et al. 2000; Gaffney et al. 2001; Jones and Playforth 2001; Mark and Shepherd 2004; Munro et al. 2005; Lambert et al. 2013). There is also a considerable body of literature which attends to the experiences of nurses working in the service. For example, studies have considered the impact of working in a call centre setting on nurses' job satisfaction (Knowles et al. 2002) and professional identity (Mueller et al. 2008; Snooks et al. 2008; Snelgrove 2009); the interaction between nurses and the decision-making software used in NHS Direct (Smith 2010; O'Cathain et al. 2004; Greatbatch et al. 2005; Hanlon et al. 2005); and the strategies that nurses develop in order to manage the lack of visibility of patients (Pettinari and Jessop 2001; Snelgrove 2009).

There is limited representation of lay perspectives on these services in the published literature. Caller surveys, intended to measure satisfaction and the extent to which people followed the advice they had been given, were carried out as part of the evaluations of NHS Direct (O'Cathain et al. 2000), NHS 24 (Heaney et al. 2005) and NHS 111 (O'Cathain et al. 2014). Surveys have also been used, for example, to explore whether callers with specific symptoms chose to follow advice given by NHS Direct (Byrne et al. 2007) and to identify population groups most likely to use the new 111 service (Knowles et al. 2014). A small number of papers have drawn on interviews with callers to NHS Direct. Three of these (Goode et al. 2004a; Goode et al. 2004b; O'Cathain et al. 2005) were outputs of a research project entitled 'NHS Direct: Patient empowerment or dependency' (Hanlon et al. 2003) which aimed to examine 'issues of risk, trust, knowledge, empowerment and dependency in welfare and to test empirically the notion of the "reflexive citizen"' (Goode et al. 2004b: 314-5). These papers explore the ways in which callers interact with NHS Direct in the

co-construction of their health care and of the service itself. They question the extent to which patients are actually active participants in their own care and the extent to which NHS Direct may empower them to be so. As such, they illustrate the links between the new organisational form of NHS Direct and individual illness behaviour, in the context of discourses of risk and reflexivity. These papers will be discussed more extensively below.

Apart from satisfaction surveys, there is a complete absence of published research exploring the perspectives of callers to NHS 24. One unpublished study (Ireland 2012) used in-depth interviews with mothers of young children who had called NHS 24 to explore their use of the service. More recently, a large-scale national study interviewed people about their use of the service; findings of this research have not yet been published but a funders' report is available (Elliot et al. 2014). Therefore, there is a gap in the literature regarding illness behaviour and help-seeking decisions in the context of the current organisation of out-of-hours health care in Scotland. This is important because it has been well established that changes to the organisation and provision of health services can influence how people understand and access health care (Blaxter and Paterson 1982; Rogers et al. 1999; Mark and Shepherd 2004; Dixon-Woods et al. 2005) and, equally, that the structure and delivery of services are responsive to illness behaviour (Rogers et al. 1998; Dixon-Woods et al. 2005). It is therefore necessary to understand illness behaviour and the decisions that people make about help-seeking in the context of the entirety of the health care system that they are a part of (Kleinman 1980).

The remainder of this section explores Kleinman's (1980) model of the health care system and considers how the boundaries between the sectors are both shifting, as a result of processes of medicalisation and lay re-skilling, and permeable, as people and products move between the sectors. This leads to the generation of questions about how we might understand the role of NHS 24 in the health care system and what this means for practices of self-care.

2.1.1 The popular and professional sectors of health care

Kleinman (1980: 24) describes health care systems as systems of ‘symbolic meanings anchored in particular arrangements of social institutions and patterns of interpersonal interactions’. This is a broader conceptualisation of the system than one which refers solely to the way in which medical services are delivered within a particular context, as it allows for pluralistic understandings of illness and healing and the types of institutions and interactions in which healing can take place.

Kleinman developed a conceptual model of such a system based on an understanding of ‘how the actors in a particular social setting *think* about health care’ and from ‘studying the way people *act* in it and *use* its components’ (1980: 26 original emphasis). The model comprises 3 ‘sectors’ of health care which Kleinman terms the popular, professional and folk sectors. Image 1 shows how the three sectors are conceptualised as overlapping, with boundary lines around each sector but points of ‘interaction, entrance and exit’ between them (Kleinman 1980: 50).

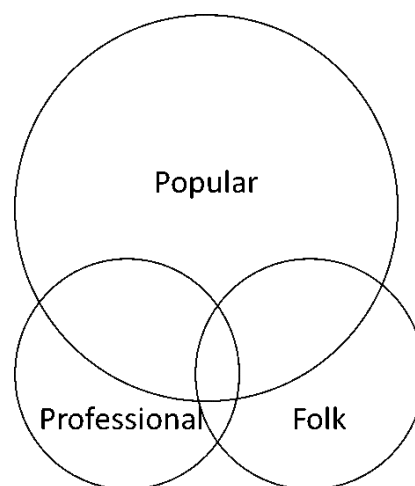


Image 1: Kleinman's model of the health care system

The popular sector is that of lay care, which includes self-care and self-diagnosis as well as care by family members or others in a person's social network. It includes the things that people do in order to stay healthy as well as actions taken to treat symptoms of illness such as self-medication, the use of home remedies or other healing strategies. The popular sector is the largest sector and it is where most symptoms or episodes of illness are dealt with (Hannay 1979; Elliot et al. 2011;

MacKichan et al. 2011). It is in the popular sector that people make decisions, often in consultation with others, about when and where to seek professional help (Kleinman 1985: 142). It is from here that people may choose to move into the professional or folk sectors and to here that people return following consultations with professional or folk practitioners. The ‘mundane caring’ which takes place in the popular sector, including looking after children or other family members when they are ill, is often highly gendered (Scambler 2002: 118).

In western health care systems, the professional sector is dominated by the formal structures of biomedicine, although Kleinman (1985: 146) points out that, in his conceptualisation of the system, the professional sector concerns not just biomedical practitioners but also indigenous professions and alternative practitioners with professionalised structures. In the UK, the professional sector contains within it many different services which are mostly integrated under the banner of the National Health Service. Although this sector is not the largest, it is the most powerful. This has led theorists such as Illich (1976: 6) to suggest the existence of a ‘medical monopoly over health care’. However, others have argued that the power of the professional sector has been increasingly challenged in recent years, as I will discuss further below.

The folk sector comprises the practices of non-professional therapists or ‘specialists’ such as herbalists, aromatherapists or faith-based healers who practice outside of institutional settings (Kleinman 1985: 149). While this thesis is primarily concerned with the popular and professional sectors and the spaces where they intersect, the folk sector can also overlap with each of these other sectors at times and it is present in some of the accounts of health, illness and help-seeking discussed in later chapters.

It is important to be mindful of the need for caution in defining health systems in ways which risk them becoming reified as ‘objects-in-themselves’ (Stoner 1986: 47). Stoner points out that health care decisions are made within a pluralistic framework incorporating many interconnected ‘spheres of existence’ such as ‘social, biological, cultural, political [and] medical’ spheres which do not function independently of

each other (1986: 47). He argues that what is important when seeking to understand illness behaviour and decision-making is a 'clear and focused study of the actual health care alternatives that people utilise in times of illness' (1986: 44). Stoner is particularly critical of what he sees as a false dichotomy between 'traditional' and 'modern' practices in the folk and professional sectors. However, he acknowledges the strength of Kleinman's model in that it recognises the way in which the sectors overlap and allows for treatments and practices to be simultaneously conceptualised as part of more than one sector. Kleinman himself emphasises that health care systems are 'socially and culturally constructed' forms of social reality (1980: 35) and that they are 'concepts' not 'entities' (1980: 25).

Kleinman's model has been critiqued as overly simplistic and potentially less relevant today than it was when first proposed, as people now have access to a broader range of information and treatments from each of the sectors and the boundaries between them are increasingly blurred (Stevenson et al. 2003). Stevenson and colleagues modified the model to meet the requirements of their study of self-treatment, distinguishing between manufactured and home remedies used in the popular sector and indicating where various treatments might fall into the areas of overlap between the sectors. The model was also modified by MacKichan et al. (2011) to reflect the results of their survey on recent use of health care for common health problems. Each of these modified models provides additional detail to Kleinman's original diagram in order to better reflect the particular concerns it is being used to discuss; however, neither adds much new conceptually. There is validity to the claim that the model is simplistic, but the ways in which it has been adapted show it still has value as a starting point from which to understand the health care system. It is perhaps its very simplicity that leaves room to explore how we interpret and designate health care behaviours and interactions as taking place in the popular or professional sectors. Furthermore, the way in which the sectors overlap gives the model particular heuristic value when seeking to understand illness behaviour in relation to an organisation such as NHS 24, which variously controls or enables access to the professional sector but also aims to support and enhance the popular sector.

2.1.2 The boundary between the popular and professional sectors

Stevenson et al. (2003: 15) suggest that each of Kleinman's sectors is 'associated with an expert body of knowledge that legitimates treatment choices' made within that sector. These different bodies of knowledge, or types of expertise, are based on different epistemological assumptions (Williams and Popay 1994). In a straightforward conceptualisation, the professional sector is founded upon claims to specialised, expert knowledge about disease and treatment which is not accessible to, or easily understood by, lay people (Freidson 1970; Scambler 2002) while the popular sector is founded on common-sense or experiential knowledge about illness (Williams and Popay 1994). However, several authors have pointed out that the distinction is not as straightforward as this (Giddens 1991; Williams and Popay 1994; Pols 2012). For example, Pols (2012) highlights that when discussing lay and expert knowledge it is problematic to view them as either completely separate or as the same. This is because defining them as different risks trivialising experiential knowledge as 'the "exotic" lay wisdom of patients' rather than 'real' knowledge (Pols 2012: 80); while to equate scientific medical knowledge with patients' knowledge 'makes the latter invisible as an object of study in its own right' (Pols 2012: 81) and may also lead to confusion about what it means to be an 'expert' (Prior 2003).

A more nuanced approach, and one which is helpful in considering the context of self-care, is to recognise that 'lay knowledge may incorporate expert knowledge but that it has to be reinterpreted in terms of the experience of everyday life' (Williams and Popay 1994: 122). In her study of telecare, Pols (2012) discusses how the different epistemologies of illness must be negotiated and combined in practices of self-care. She found that medical knowledge was constantly influencing and being incorporated into the daily lives of her participants, although often with some effort required to make it 'fit'. Like Williams and Popay (1994), Pols (2012: 95) suggests that patients must acquire 'translation' skills in order to turn the 'propositional knowledge' held by experts into 'practically useful knowledge' that enables them to deal with illness. Equally, medical knowledge can be said to incorporate experiential

and embodied knowledge as theory is enhanced and made meaningful through its use in practice (Freidson 1970; Haug 1988; Nettleton et al. 2008). This illustrates that while the explanatory models used to describe illness and healing practices may differ between the sectors of health care, the boundaries between the types of knowledge held by each sector can be blurred and shifting.

The idea of medicalisation (Freidson 1970; Zola 1972; Illich 1976; Conrad 2007) has been evoked to describe how the professional sector has come to dominate over the popular sector by establishing its claims to knowledge as more legitimate. It is claimed by theorists such as Illich (1976) that the capacity and confidence of lay people to cope with illness without recourse to professionally organised medicine has been undermined by the expansion of medical authority. This aspect of the medicalisation thesis has been critiqued by those who argue that it overstates the power of the medical profession to the neglect of other societal influences (Kleinman 1985; Rose 2007a) and that it doesn't account for the scepticism and reflexive agency of the lay public (Williams and Calnan 1996a). However, though wary of what he describes as a focus on 'the machinations of the medical profession' (Kleinman 1980: 49), Kleinman agrees with the idea that the professionalisation of health care has undermined the popular sector in western society, for example by restricting 'access to drugs and to the knowledge and resources required to use them' (1985: 143). He suggests that processes of social change in western societies – particularly industrialisation, urbanisation and modernisation – have led to the weakening of the popular sector because family networks have become more limited, meaning that people are less able to mobilise support in response to illness and that 'traditional knowledge' is diminished (Kleinman 1985: 143; see also de Swann 1990).

The idea that the popular sector has been eroded rests on certain assumptions about the way in which health care is enacted in that sector and may be questioned in light of new forms of social networks and ever-increasing access to resources, information and over-the-counter pharmaceuticals. It has been challenged by studies demonstrating the extent to which symptoms are dealt with in the community (Hannay 1979; Elliot et al. 2011), the popularity of self-care strategies for managing

minor illness (Porteous et al. 2007) and the ways in which people draw on and manipulate different forms of knowledge and expertise in their everyday health and illness decisions and practices (Dew et al. 2014). The idea of ‘lay re-skilling’ (Williams and Calnan 1996a) has been evoked to account for the ways in which increased access to information, for example via the internet (Hardey 1999; Nettleton and Burrows 2003), has in some ways redressed imbalances of power by giving lay people access to specialist knowledge previously unavailable to them. The process described by Pols (2012) of patients incorporating expert knowledge into their self-care practices could be interpreted as an example of medicalisation, in that medical knowledge is infiltrating and altering the everyday practices of care in the popular sector, but at the same time it may be interpreted as an example of lay re-skilling or the re-appropriation of knowledge (Giddens 1991) as access to expertise and technologies of care allows lay people to find new ways of dealing with illness in the popular sector.

Nevertheless, it is unclear how pervasive lay re-skilling is in reality (Williams and Calnan 1996a). While increased access to health information and an emphasis on patient-centred care is likely to have decreased the knowledge gap between clinicians and patients, the knowledge of most lay people still won’t match that of professionals (Haug 1988; Prior 2003). Access to information via the internet may alter the clinician-patient relationship as professionals have lost their position as the sole producers and regulators of medical knowledge (Nettleton and Burrows 2003); however, as Nettleton and Burrows (2003) point out, lay people’s reflexive engagement with this knowledge is more difficult than is often supposed and unequal access to information technology and skills is likely to perpetuate structural inequalities. While the medical profession is subject to more criticism than it might have been in the past, many lay people still retain respect for doctors and faith in medical science (Williams and Calnan 1996b; Lupton 1997). So there is a paradox, noted by Lupton (2012) that we continue to look to scientific medicine for solutions to our social and medical problems, while at the same time becoming disillusioned with it and resenting our reliance on it. In this sense, processes of both medicalisation and de-medicalisation are at work simultaneously (Williams & Calnan 1996) and

questions still remain as to whether lay people's knowledge and confidence to self-care is being eroded or enhanced by new forms of health care provision.

Kleinman's model of the health care system presents the 3 sectors of health care as overlapping circles and we can see how the boundaries between them may shift in response to these processes of medicalisation and lay re-skilling, though how this is understood depends on how the sectors are conceptualised. As well as the boundaries between the sectors being movable, they are also permeable as patients can pass between them, moving from one sector into the next and back again over the course of an illness or during different illness episodes, or drawing on resources from more than one sector simultaneously. Increased access to knowledge has the potential to blur these boundaries further and in particular to enable medical pluralism as people explore and combine approaches to health from the popular, professional and folk sectors (Hardey 1999), particularly in practices of self-care or self-treatment (Stevenson et al. 2003; Dew et al. 2014). New organisational forms which aim to support or enhance self-care, such as NHS 24, thus raise interesting questions about the boundaries between the popular and professional sectors of health care.

While previous research on NHS Direct has considered the ways in which it may empower patients in making decisions about their own care (O'Cathain et al. 2005), there has been no research on how access to NHS 24 may impact on practices of self-care within the popular sector in Scotland. This is particularly interesting given that NHS 24 is a service which aims to support and enhance capacity for self-care, both for minor illnesses and long-term conditions. Stevenson et al. (2003: 515) suggest the possibility that NHS Direct 'endorses certain types of self-treatments such as home remedies and over the counter medicines' and that the service, alongside publicity campaigns urging people to make greater use of community pharmacies, may make people feel more comfortable about discussing their use of self-treatment 'as they can quote a "legitimate" source of advice'.

Stevenson et al. (2003: 517) posed, but did not attempt to answer, the question of whether the introduction of NHS Direct might be conceptualised as either 'legitimation' or 'colonisation' of the popular sector. This is an interesting question

which can also be applied to NHS 24, with implications for how we understand the role of such a service within the health care system and indeed for how we understand ‘self-care’. Although the authors did not elaborate on what they meant by these terms, I suggest that NHS 24 might be a source of ‘legitimation’ if it enables people to obtain professional sanction for self-care practices which might be seen as less legitimate than medical care. On the other hand, shifting care ‘from the surgery to the sitting room’ (Pencheon 1998: 215) could be understood as the encroachment of the professional sector into the realm of the popular sector in a form of medical ‘colonisation’. Both of these terms suggest varying degrees of medicalisation (Conrad 2007), although the distinction lies in whether the legitimacy of the popular sector is being enhanced or undermined. Of course, both or neither of these things may be happening but it is nevertheless an interesting line of enquiry. In order to explore this further, it is necessary to have an understanding of NHS 24 and the context in which it operates, to which I turn in the next section.

2.2 NHS 24

In the previous section I established the position that in order to understand the ways in which people use NHS 24 and how their use fits with their illness behaviour more generally, it is necessary to explore the organisational context of NHS 24 and its place within the health care system. The organisation’s history is of great relevance here as the way in which it was introduced, what it promised to deliver, the expectations that were set out, the way it has been advertised to the public and the ways it has been portrayed in the media have all served to shape how the service is understood and used. The early part of this history has been comprehensively documented as part of the review of the implementation of NHS 24 (Heaney et al. 2005) and I draw on this review in order to highlight the operational challenges faced in the early stages of NHS 24’s implementation and the consequences of these early challenges for the development of the service. In particular, I highlight the emergence of competing imperatives for NHS 24 to enhance access to health care while at the same time managing demand by encouraging self-care. This must be considered in the broader context of health policy in the UK and Scotland, which is focussed on individualised discourses of responsibility and the imperative to ‘shift

the balance of care' from the professional to the popular sector; so it is with an outline of this context that this section begins.

2.2.1 Policy context

Two of the central policy drivers which have led to the introduction of NHS 24 are a neo-liberal preoccupation with active and engaged citizens taking responsibility for their own lives and their own health (Armstrong 1995; Petersen and Lupton 1996; Rose 2007b), and the age-old issue of demand for health care putting a strain on limited resources (Rogers et al. 1999). It is easy to see how the former may come to be seen as part of the solution to the latter; the theory being that if people can be enabled (or persuaded) to look after themselves and to only use health services when they need them then demand will be reduced (Rogers et al. 1998). Of course, this is premised on an assumption that many people don't already look after themselves and that they use services unnecessarily. In fact, a study of patients with long-term respiratory conditions (Kielmann et al. 2010) found that patients were aware of the increasing policy focus on self-care but found the term to be incongruous because it describes something that they already do as a matter of course. These policy drivers have been described in terms of a 'deficit model' based on the need to cut costs in the health service and reduce GP and emergency department attendances, and a 'self-determination model' based on the idea that people are ready and willing to self-care and that professionals are prepared to support them to do so (Haly 2012). Haly argues that there is evidence to support the self-determination model but that government and NHS policies seem to be (implicitly) based on the deficit model.

Individual responsibility and self-care

Almost 30 years ago, Kleinman (1985: 143) predicted that there would be a move amongst health care policy-makers, in spite of professional resistance and ideological barriers, to shift care from the professional to the popular sector, primarily 'in the interest of cost containment'. This prediction has been largely borne out in the development of UK health policy over recent decades, as the rhetoric of active citizenship and individual responsibility for health and health service use has become increasingly prevalent across the political spectrum. For example, the 1996 Conservative white paper, *The National Health Service: A Service with Ambitions*,

refers to helping people to ‘make more appropriate and responsible use of services and take greater responsibility for their own health’ (Department of Health 1996: page n/a) and an emphasis on responsible, active citizenship was also a key tenet of New Labour’s Third Way (Scambler 2002; Klein 2010). The first New Labour white paper on health, *The New NHS: Modern. Dependable*, announced the introduction of an NHS Charter which would set out patients’ rights but also their ‘responsibility to use services wisely’ (Department of Health 1997: §1.19).

Although Scottish health policy began to diverge quite significantly from that of the rest of the UK after devolution, especially in terms of how the health service would be structured, the different jurisdictions faced similar challenges of ageing populations, more people with long-term conditions, scarce resources and almost unlimited demand (Greer 2004). Scotland’s post-devolution plan for the NHS, *Our National Health* (Scottish Executive 2000), which announced the introduction of NHS 24, continued the theme of individual responsibility for health, but emphasised the importance of services, communities and individuals working in partnership to improve health; thus introducing a more collaborative tone than that found in UK policy, while still using the terminology of neo-liberalism and the ‘new public health’ (Petersen and Lupton 1996). The white paper which followed 3 years later, *Partnership for Care*, had ‘encouraging greater personal responsibility’ as a key theme (Scottish Executive 2003: 17), again with an emphasis on partnership and public involvement. *Partnership for Care* also began to introduce the language of ‘shifting the balance’ of care between hospital and community settings and introducing new models of care.

In 2005, the Kerr report, *Building a Health Service Fit for the Future*, highlighted the issue of rising demand and again talked about a need to shift the balance of care into community settings and to encourage and facilitate self-care. The report continued the theme of collaboration and partnership but also put a specific emphasis on the need for individuals to take responsibility not only for their own health, but for ‘the overall effectiveness of the health system’ (Scottish Executive 2005a: 5). The action plan produced in response to the Kerr report, *Delivering for Health* (Scottish Executive 2005b), highlighted support for self-care as a key priority, though most

notably in relation to people with long-term conditions. Two years later, the *Better Health, Better Care* action plan (Scottish Government 2007) announced the development of a self-management framework. This strategy, *Gaun Yersell!*, launched in 2008, calls for people to have better access to information and support to manage long-term conditions but notably does not include reference to self-care for minor illnesses or injuries (Scottish Government and the Long Term Conditions Alliance Scotland 2008). Policy discourse on the use of technology to enhance self-care has also focussed on long term conditions, as outlined in the eHealth Strategy for Scotland (Scottish Government 2011).

Better Health, Better Care also announced the introduction of a Patients' Rights Bill for Scotland. This was passed in 2011, followed by a Patient's Charter (Scottish Government 2012) which balanced these rights with a series of responsibilities, including that people 'should use health services responsibly' (Scottish Government 2012: 8) and 'take some personal responsibility for [their] own health' (Scottish Government 2012: 11). Most recently, the *Healthcare Quality Strategy for NHS Scotland* reaffirms the commitment to a mutual NHS, in which every individual has responsibility for 'learning, taking action to maintain their own health, managing their ill-health, collaborating in respectful partnerships with healthcare staff, and feeding back their experiences and outcomes to support a continuous cycle of improvement' (Scottish Government 2010: 42). The *Quality Strategy* emphasises a commitment to people being seen in the right place, by the right person, at the right time – language which has been taken up in publicity materials encouraging people to use services appropriately, such as the 'Know Who To Turn To' campaign which is discussed further in section 2.3.2 below.

The UK Government has also continued to push the self-care agenda, though with a much more inclusive definition of self-care which is closely aligned with Kleinman's concept of the care provided in the popular sector and incorporates both care for long-term conditions and minor ailments:

Self care is a part of daily living. It is the care taken by individuals towards their own health and wellbeing, and includes the care extended to their children, family, friends and others in neighbourhoods and local

communities. Self care includes the actions people take for themselves, their children and their families to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long-term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital (Department of Health 2005: 1).

The UK Government has set out clearly where support for self-care sits in relation to the whole system of health and social care (Department of Health 2005). In contrast, Scotland's emphasis on supported self-management for people with long-term conditions reveals a gap in Scottish health policy regarding efforts to enhance or enable self-care for minor illness and injuries.

As Wilkinson and Whitehead (2009) note, the 'rights and responsibilities' approach of UK health policy means that self-care is not only a right (and therefore potentially empowering) but also a responsibility (and therefore a potential burden). An emphasis on self-care, empowerment and responsibility may fail to take account of the structural barriers that patients face (Anderson 1996; Chapple and Rogers 1999), leading to a focus on individuals rather than on social and economic inequalities and creating the potential for 'victim-blaming' (Dean 1986; Segall and Goldstein 1989). The introduction of services such as NHS Direct and NHS 24 is framed as empowering patients by enabling self-efficacy; however, this focus 'lacks acknowledgement of the problematic nature of empowerment' (O'Cathain et al. 2005: 1763). Segall and Goldstein (1989: 160) warn that an emphasis on self-care may be used as a 'justification for decreasing the level of formal health services provided'. Similarly, Chapple and Rogers (1999) suggest that policy makers view self-care as a 'hidden health care resource' which will produce economic savings, but they note that evidence on the effects of policies to promote self-care is mixed.

Managing demand

Management of demand is a consistent policy concern, which has become a 'headline issue' in the UK, particularly since NHS reforms introduced in 1991 (Klein 2010: 177), but it is rarely explicitly addressed in health policy due to unpalatable connotations of rationing (Rogers et al. 1999). Of course, what is understood by 'demand' for health services, and whether or not rising demand is considered to be

problematic, is contingent on the social and political context (Rogers et al. 1999). As de Swann (1990: 107) argues, symptoms or illnesses do not ‘in themselves inspire a “need for medical treatment”’, but rather the idea of consulting a clinician about illness has become so ‘vested in the nature of things’, that it masks the ways in which demand and need are socially constructed.

The introduction of NHS Direct (and later NHS 24 in Scotland) was seen by some as playing a key role in managing demand through enabling appropriate health service use and empowering people to self-care (Pencheon 1998), thus, in theory, reducing demand for other services and ultimately costs to the NHS. Consequently, much early commentary and research has focussed on the impact of NHS Direct on other services, but the evidence has been equivocal. Two studies showed that emergency departments and ambulance services didn’t seem to be affected by the introduction of NHS Direct, though there was a small but significant reduction in net demand for out-of-hours GP services (Munro et al. 2000; Munro et al. 2005). These studies didn’t consider the impact on in-hours demand and couldn’t distinguish those calls that may previously have resulted in telephone advice from a GP co-operative; therefore the researchers couldn’t make any claims about overall demand or impact on face-to-face contacts and were unable to identify if demand was just being deferred, a possibility suggested by Bunn et al. (2004). A more recent study (Lambert et al. 2013) found an impact on other services when comparing NHS Direct advice with what respondents said they would have done had NHS Direct not been available. However, this has to be interpreted with care as it is based on people’s retrospective accounts of potential behaviour.

There were concerns expressed when NHS Direct was introduced that improved telephone access may actually create ‘supplier induced demand’ (Salisbury et al. 2000; Smith et al. 2001), with one editorial highlighting a risk that the service was merely meeting ‘previously unexpressed demand among the worried and well middle classes’ (BMJ 2002: 559). Gaffney et al. (2001) compared patients referred to 999 by NHS Direct with those who self-referred and found that the NHS Direct group tended to be younger and had suffered symptoms for longer, whereas those who had self-dialled 999 were more likely to have experienced trauma, suggesting a

possibility that the NHS Direct group was a new cohort who would not previously have arrived in A&E by ambulance. However, the researchers noted that they represented a tiny proportion of cases and concluded that NHS Direct was likely to have minimal impact. Jones and Playforth (2001) noted a reduction in advice calls dealt with by A&E staff but a huge increase in calls to the hospital in which their study was sited. They suggested a possibility that NHS Direct may have stimulated demand for health information from the public. While it is still too early to fully measure the impact of NHS 111, evaluation of the pilot sites found no impact on emergency and urgent care service use but a small increase in the number of ambulances sent to patients, suggesting that it could potentially increase demand for services across the emergency and urgent care system (Turner et al. 2013).

In Scotland, emergency department, ambulance service and NHS 24 activity have all increased in recent years (Audit Scotland 2010). For the ambulance service, emergency calls have increased while urgent calls have decreased. For NHS 24, calls that result in a 999 call have increased, although calls that result in the patient being advised to go to an emergency department have fallen (2010: 10). Emergency department staff surveyed by Audit Scotland said that they believe the introduction of the new GP contract and the roll-out of NHS 24 have increased demand for emergency department services because ‘NHS 24 is overly cautious and refers some patients unnecessarily’ (Audit Scotland 2010: 32). However, NHS 24 referrals account for less than 4 per cent of emergency department attendances and ‘are unlikely to have had a significant impact on workloads at emergency departments’ (Audit Scotland 2010: 10). Rather, Audit Scotland suggests that the 4 hour waiting time guarantee in emergency departments may explain why people choose to be seen there rather than waiting up to 48 hours for a GP appointment, showing how policy can have unintended impacts on illness behaviour.

The introduction of services such as NHS 24 seems to be the ideal way to combine the aims of fostering responsible citizenship and self-surveillance with the idea that providing people with ‘correct’ information and advice will enable them to make ‘rational choices about their use of health services in ways that accord with a rational allocation of resources (“the most appropriate use of NHS services”)’ (Goode and

Greatbatch 2005: 319). However, although Kleinman predicted the policy shifts described here, he also warned that ‘the determinants of change in the popular sector are long-term historical processes of economic and socio-political power that cannot easily be reversed and may even accelerate in the future’ (Kleinman 1985: 144). The complex processes of medicalisation noted in the previous section and the inconclusive evidence on the impact of changes that have been introduced show the difficulties in using policy drivers to stem the apparent shift in help-seeking from the popular to the professional sector.

2.2.2 Helplines and telephone consultation

Telephones have been used to seek medical assistance since they were first invented (Hallam 1989) and specialised telephone helplines have existed for over 60 years (Firth et al. 2005). Helplines began to proliferate in the 1970s and 1980s and Firth et al. (2005: 11) describe them as both a product of and an instantiation of ‘our consumer-driven “information age” and its growing and apparently insatiable need for rapid access to specialised knowledge’. They claim that the fundamental attraction of helplines is that they offer *accessibility* to expertise and knowledge and much of the marketing of helplines emphasises this accessibility, with messages such as ‘just call us’ and ‘we’re here to help’ suggesting to the public ‘that help is “on tap” and, moreover, that their “problems” are helpable and, indeed, helpable over the telephone’ (Firth et al. 2005: 17). At the same time as being a response to demand for access to expertise, Firth et al. (2005: 12) suggest, following Rose (1999), that helplines are ‘*creating* a here-and-now need for expertise, in the form of information, guidance, advice, solace and/or emotional support, in a wide range of human affairs’ (Firth et al. 2005: 12 original emphasis). This is consistent with the idea that services such as NHS Direct and NHS 24 may stimulate demand for expertise by their very existence, but also raises questions about how expertise is being constructed in this discourse given that helplines are often operated by trained volunteers or peer supporters drawing on a hybrid of lay and professional knowledge.

While the use of the telephone to seek medical help is by no means a new phenomenon, for a long time telephone consultation was quite rare in the context of

UK primary care compared to other countries and it was not favoured by either professionals or patients (Hallam 1989). More recent studies have found increased interest in using telephone consultation amongst both clinicians and patients, but GP and patient views on consultations which are suitable for the telephone differ (Stevenson et al. 1998; Kernick et al. 1999; Neal et al. 2004). One review (Car and Sheikh 2003) found that patients were generally satisfied with the telephone as a means of consultation, particularly those in rural areas, and that clinicians also saw benefits to telephone consultation although many were uneasy about the potential risks of missing something serious. A Cochrane review of research on telephone consultation (Bunn et al. 2004) found no evidence of an increase in adverse effects; however, the authors point out that the evidence on cost, safety and effectiveness is limited.

The Cochrane review also found that telephone consultation reduces immediate face-to-face GP consultations and doesn't appear to increase emergency department visits (Bunn et al. 2004). This review suggests that at least 50 per cent of calls can be handled by telephone advice alone, although 2 of the studies reviewed showed an increase in return visits to the GP, signifying that telephone consultation or triage may just delay face-to-face consultation. Pinnock et al. (2005: 910) note that this finding is unsurprising, as telephone advice might not be acceptable to patients in situations where 'requests for face-to-face appointments or home visits are intercepted by a clinician (usually a nurse) who may address the problem or allocate "appropriately", potentially overriding the patient's original choice of provider and mode of consultation', leading them to seek a face-to-face consultation at the next available opportunity. This is echoed by O'Cathain et al. (2005) who note that callers to NHS Direct sometimes felt that it limited their options as it was the only route available to accessing a GP out-of-hours and if they were obstructed they would bypass the system by attending an emergency department.

Few studies have focussed specifically on how patients experience telephone consulting, although some do include patient views alongside staff views; for example one study which found that patients saw telephone consulting as easier to access than face-to-face appointments and that 'full-time workers, parents, poorly

mobile patients, and those living at a distance found the facility useful' (McKinstry et al. 2009: e212). Rural patients used the telephone to overcome problems of distance and to determine if a visit to the doctor was really necessary. Both clinicians and patients expressed anxieties about lack of visibility but these concerns were allayed to some extent if the clinician and patient knew each other already (McKinstry et al. 2009). There is still very little evidence on how telephone consultation is experienced as part of the patient journey and to what extent it is understood as enhancing or legitimating self-care.

2.2.3 NHS 24: Implementation and early challenges

Prior to the introduction of NHS 24 in Scotland, out-of-hours organisations had developed locally in response to the needs of the population, geography, available resources and the history of local service provision (Thomson et al. 2003). There were over 60 different organisations providing out-of-hours care, with considerable differences in how they were structured, particularly between urban and rural areas, and these organisations generally showed 'little evidence of formal integration with other services' such as A&E departments, social work, community nursing and mental health services (Thomson et al. 2003: 200).

The introduction of NHS 24 was announced in the Scottish Executive White Paper *Our National Health: A plan for action, a plan for change* which promised 'advice and access to care all day, every day in a single telephone call' (Scottish Executive 2000: 10). NHS 24 was set up as a special health board in 2001 and phased roll-out of the service began in 2002. The first contact centre, in Aberdeen, came on line in May 2002, with the Clydebank centre following just 6 months later, in November, and the South Queensferry centre in September 2003. The programme of integration with other out-of-hours services and health boards continued until November 2004. Local satellite centres opened in NHS Ayrshire and Arran, NHS Dumfries and Galloway, NHS Highland, NHS Lanarkshire and NHS Tayside in 2005.

The circumstances surrounding the implementation of NHS 24 have been extensively documented in an independent evaluation published a year after the service was fully

established (Heaney et al. 2005). This evaluation was commissioned by the then Scottish Executive Health Department and its aims were:

to examine the impact of the service on its integrated partners, gather views of patients using the service, describe the quality and consistency of service delivery, explore and explain the impact of implementation and to conduct an economic evaluation of the service (Heaney et al. 2005: 27).

The evaluation was originally to be carried out over 32 months but it was extended in 2004 in order to respond to changes in the implementation plan. A model of ‘realistic evaluation’ was used in order to allow in-depth enquiry into mechanisms and contexts (Heaney et al. 2005: 29) and the resulting report is the only comprehensive account of the organisational context of NHS 24 at its origins and of its early reception by patients and partners.

From the beginning, NHS 24 was designed to be integrated with local partners such as GP cooperatives, the Scottish Ambulance Service and emergency departments and to forge close links with the 14 territorial health boards. However, the organisation experienced initial difficulties in its relationships with partners, and in particular with GP cooperatives (Haddow et al. 2007). The evaluation (Heaney et al. 2005) identified part of the reason for the difficulties as being the complex organisational landscape, mentioned above, into which NHS 24 had to integrate.

Arguably the biggest challenge in the organisation’s history came in 2004 with the introduction of the new General Medical Services (GMS) contract which allowed GPs to opt out of responsibility for providing out-of-hours care. In Scotland, 95 per cent of practices had chosen to opt out by December 2004 (Audit Scotland 2007), leaving the territorial health boards with responsibility to provide out-of-hours primary care for their populations. NHS 24 had always been designed to co-ordinate out-of-hours care in collaboration with GP cooperatives but it had been intended as ‘supplementary to and not a substitute for GP out of hour services’ (Godden et al. 2011: 163). Now, the territorial NHS boards turned to NHS 24 to take on responsibility for the workload and the service quickly became the first point of contact for all out-of-hours primary care. As this new development coincided with the busy winter period of 2004-05, NHS 24 struggled to cope and was heavily

criticised in the media (Gray 2005; Henderson and Gordon 2005; Rodrick 2005) and by politicians (Scottish Parliament 2004; 2005a; 2005b; 2005c). This was further compounded by extensive negative press coverage of the service when a Fatal Accident Inquiry was ordered into 2 deaths that had occurred in September 2004 and December 2004 (Nutt 2005; Ross 2005), contributing to perceptions of a service in crisis.

An independent review was commissioned by the Minister for Health and Community Care in early 2005 in response to the criticisms of NHS 24, with a remit to look at a number of specific challenges and to make recommendations. The review (NHS 24 Independent Review Team 2005a: iii) was to focus on improving the responsiveness of NHS 24 to callers; reducing waiting times and the use of ‘call-back’; improving services for patients in remote and rural areas; improving hand-over of patients between NHS 24 and its partners; and addressing staffing issues. The review team spoke to a broad range of stakeholders and were frank in their criticism of mistakes that had been made and in their advocacy of the need for change. They published an interim report (NHS 24 Independent Review Team 2005b) 9 weeks into the review period which was arguably more critical than the final report would be. The media proclaimed that the interim report ‘savaged’ NHS 24 (BBC News 2005) and the then chief executive made a public apology on its release. The review found that, in hindsight, NHS 24 had not been ready for the changes brought about by the introduction of the new GMS contract but that it had failed to recognise this in time and had continued to reassure other NHS boards that it would be capable of meeting demand.

The independent review also heavily criticised the use of call-back, which it described as by far the biggest problem NHS 24 had at the time. Call-back had been used prior to the introduction of NHS 24 by many GP cooperatives to manage and prioritise calls (Heaney et al. 2005), but this was usually ‘managed use of call back’ to deal with unexpected increases in demand over a short period of time (NHS 24 Independent Review Team 2005a: 18). The use of call-back ‘was never intended to be an integral part of day-to-day working in NHS 24’ as ‘NHS 24 was specifically not designed for its use’ (NHS 24 Independent Review Team 2005a: 18); yet it was

being used within weeks of the service being implemented and it is still in use today, suggesting that, although the recommendations of the review were acknowledged, there have been barriers to implementing some of them.

The evaluation (Heaney et al. 2005) and the review (NHS 24 Independent Review Team 2005a) were both written to serve the purpose of documenting and commenting on the implementation of NHS 24. They are strong studies, with the evaluation in particular taking place over an extended timescale, using a variety of methods of data collection and analysis and considering the views of a range of stakeholders. The independent review was not a research study and was less structured in its methods, but again it considered the views of a broad range of stakeholders and was more overtly critical than the evaluation. Both of these reports provide rich and vital contextual information about the circumstances in which NHS 24 came to be and its early reception, which remain key to understanding how people now perceive and use the service. It is also necessary to understand what the service aimed to do and what it promised to offer to the Scottish public.

2.2.4 A gateway to the NHS?

From the beginning, NHS 24 was presented as being designed to enhance access to health care. The white paper which announced the introduction of the service stated that ‘traditionally, GPs have been seen as “gatekeepers” to the NHS. In future, we want to provide people with “gateways” to the NHS’ (Scottish Executive 2000: 42). In keeping with this aspiration to low-threshold access, the original aims of NHS 24 clearly show that the role of the organisation was to provide advice and support in non-emergency situations. The stated aims (NHS 24 Independent Review Team 2005a: 3) were to:

- offer reassuring health advice to, for example, parents of young children or the elderly living alone who have worries about their health which may not be serious enough for a GP contact;
- build better links among GP out-of-hours services, out-of-hours social work services, and other secondary care services; and
- provide a better, more appropriate response to 999 callers who do not require the immediate dispatch of an ambulance.

However, once this gateway to the NHS was opened, people, unsurprisingly, began to use it. The independent review refers extensively to the effect of early marketing efforts which created somewhat unlimited expectations of the service:

In its early days NHS 24 obviously had to publicise its presence and it did a lot of good promotion work. But in its enthusiasm and perhaps because the workload was then relatively light, it seems at times to have gone just too far. The ‘we are just a call away’ and ‘call us any time’-type messages suggested that callers could indeed call – virtually at any time, day or night, and for almost any reason. No-one could begin to blame the general public if they took up that open offer (NHS 24 Independent Review Team 2005a: 9).

As well as encouraging unlimited use, the report suggested that NHS 24 had ‘failed to explain to the public at large that during out-of-hours periods its main service was intended primarily for callers who felt they had an urgent need for help or advice’ (NHS 24 Independent Review Team 2005a: v). This is interesting, as the white paper which announced the introduction of NHS 24 refers to ‘24-hour access to advice’ but does not make any reference to this being for urgent situations only (Scottish Executive 2000: 41). It is unclear at what point it was decided that NHS 24 should only be used for urgent symptoms in the out-of-hours period and it seems to have been something of a U-turn brought about as NHS 24 struggled to cope with increasing demand as a result of the changes to the GP contract. It is evident that from the very beginning there has been a lack of clarity of purpose around NHS 24, and, as I will discuss further in chapter 4, its role has not become any clearer.

Opening a gateway to the NHS is inconsistent with the imperative to manage demand and the 2005 review team argued that the messages being communicated to the public must be changed in order to persuade people that they should only call NHS 24 in the out-of-hours period if they had an immediate need for attention. However, they acknowledged that this is not an easy message to convey. Even while advocating more restrictions on use of the service, the interim report referred to the principle that ‘no-one who needs the help of the NHS must ever hesitate to call - at any time. That applies most of all to calls concerning the elderly and the very young’ (NHS 24 Independent Review Team 2005b). The people who should be asked to avoid calling at peak times were those ‘who want very general advice, and who have

no immediate problem whatsoever' (NHS 24 Independent Review Team 2005b). Of course, what constitutes an 'immediate problem' is not always apparent and can depend very much on the individual perspective and context. There is a clear tension here between improving access and encouraging people not to ignore worrying symptoms, while also rationing a limited resource. NHS 24 is attempting therefore, in its service provision, to fulfil two seemingly incompatible roles.

The 2005 review found 'indications that in some [geographical] areas the role of NHS 24 was never properly explained' and that there was 'fairly widespread lack of understanding of the new OOH arrangements' (NHS 24 Independent Review Team 2005a: 21). For some people, particularly those in rural areas, the introduction of NHS 24 represented a considerable change in arrangements for access to out-of-hours care. The review suggested that this may have led to some distrust of the service, which 'has perhaps been exacerbated on occasion either by personal or third-party experience of the actual service' (NHS 24 Independent Review Team 2005a: 20).

Despite the challenges facing NHS 24 and the considerable scrutiny that it was under at the time, *Building a Health Service Fit for the Future* (Scottish Executive 2005a) reaffirmed the role of the organisation in the long-term delivery of health services in Scotland. Since then, the remit of NHS 24 has grown and it now provides a broad range of additional services through a number of different media channels. The national health information and support service announced in *Better Health, Better Care* (Scottish Government 2007) became operational in 2010 as NHS Inform, under NHS 24's remit, providing online health information and a national health information helpline. The Scottish Centre for Telehealth and Telecare was integrated into NHS 24, also in 2010, cementing the organisation's role in the national provision of telehealthcare. Currently, NHS 24 is expected to further the ambitions of the *Quality Strategy* by encouraging self-care, improving access to services and managing demand through the use of telephone and online information and advice.

In recent years, improvements have been made to NHS 24's systems and procedures, such as gaining access to the Emergency Care Summary and Palliative Care

Summary, the introduction of call streaming, the use of pharmacists and dental nurses to manage calls and the training up of call handlers to be able to advise and either discharge or refer certain categories of patients. Better local knowledge and service provision has been developed, including the establishment of a presence in every territorial health board area. The Scottish Ambulance Service has also co-located all 3 of its dispatch centres with NHS 24 call centres. Alongside the expanding range of services provided, use of the unscheduled care service has grown to the point that it now receives almost 1.5 million calls per year (NHS 24 2013).

In spite of the warnings issued by the 2005 review, NHS 24 continues to send out mixed messages about its role. The current recorded message that people hear when they call NHS 24 includes the line: *'This service is for patients who require urgent medical attention that cannot wait'*. However, the NHS 24 website conveys a somewhat more general definition of what the service is for, as it states that: 'NHS 24 is here to help you. We're an online and telephone-based service. We can answer your questions about your health and offer advice' (www.NHS24.com/explained). Part of the disparity undoubtedly stems from the fact that 'NHS 24' refers to the organisation as a whole, across all of its many platforms, so NHS 24 is indeed happy to offer general information and advice, just not through its main phone line in the out-of-hours period. Ideally, non-urgent information and advice are provided primarily by the health information service as well as via the online platforms NHS24.com and NHS Inform and the digital television channel. However, these services may be less well known and it is not made explicit in publicity materials that it is these services that provide general advice rather than the unscheduled care service which is likely to be what most people think of as 'NHS 24'.

In addition, the NHS 24 website states that 'NHS 24 is an online and *out-of-hours* phone service providing the Scottish people with access to health advice and information *24 hours a day, 365 days a year*' (www.NHS24.com/explained/services, my emphasis). Although the phone line is available during the day, the service provided is different in the in-hours and out-of-hours periods, meaning that people may experience the service differently depending on when they call. This situation, where an 'urgent care' service also offers information, advice and reassurance and

where messages promote an out-of-hours service that is available 24 hours a day, arguably creates ambiguities which must then be negotiated by callers in determining how, when and for what purpose they should use the service.

2.3 Illness behaviour and ‘appropriate’ help-seeking

Much has been written about the concept of illness behaviour and the factors which affect decisions to consult a health professional about symptoms. Over 50 years of empirical research across a range of disciplines has produced numerous theories and models (Young 2004; Wyke et al. 2013), from micro-sociological accounts such as that of Parsons (1951) to those that take greater account of the institutional and structural influences on behaviour, including the organisation of services and their accessibility (Andersen 1995). As the literature is so extensive, the need for more research in this area has been questioned (Wyke 2003) but, in spite of all we know, there are still areas in which research is limited; for example with regard to ‘how new forms of provision (such as telephone advice lines) influence the decision-making process’ (Wyke 2003: 56). It has also been noted that there has been a far greater emphasis in medical sociology on experiences of chronic illness than on experiences of acute illness (Lawton 2003); in particular the sorts of minor ailments that may be amenable to self-care. New forms of service provision and ongoing policy concerns therefore open up new areas of interest with regards to illness behaviour.

In this section, I explore the ways in which patients must negotiate the sometimes competing demands of managing risks and the responsible use of health services. It is not my intention to produce an exhaustive review of the literature on illness behaviour here, but rather to focus on key insights which help us to understand how people negotiate choices about help-seeking for non-emergency symptoms in the out-of-hours period, particularly in the context of socially constructed ideas of ‘appropriateness’. Fundamental to any consideration of whether or not help-seeking is appropriate is an alignment of the urgency of the illness with the help sought. This relies on both an ability to assess symptoms and a knowledge of how to negotiate the health care system and make choices about service use based on categorisation of symptoms, for example as ‘minor’, ‘urgent’ or ‘emergency’ – categories which are

highly subjective and contingent. In addition, the interpretation of symptoms and decisions about help-seeking must be understood in the context of what has been termed the ‘risk society’ (Beck 1992). People are increasingly exposed to public health messages and warnings about serious illness. We are told that worrying symptoms shouldn’t be ignored and that, if unsure, professional advice should always be sought, especially for children. It is in this environment of risk-awareness that people must evaluate the urgency of symptoms and determine what to do about them.

2.3.1 Illness behaviour, self-care and help-seeking

The concept of illness behaviour refers to ‘the ways in which given symptoms may be differentially perceived, evaluated, and acted (or not acted) upon’ by individuals (Mechanic 1962: 189). Illness behaviour is socially constructed (Mechanic 1986), in that the classification of a ‘problematic experience’ (Dingwall 1976) as an illness is the result of an interpretive process (Zola 1973; Locker 1981; Jutel 2011a, Rosendal et al. 2013) influenced by a range of factors such as an individual’s conceptualisation of health and illness (Herzlich 1973; Helman 1978; Stainton-Rogers 1991; Flick 2000; Blaxter 2004); socio-demographic factors (Campbell and Roland 1996); and the social or cultural context in which a person lives (Freidson 1960; Zola 1973). Once a problem is identified as an illness, the way it is responded to and whether or not help is sought is again influenced by a variety of factors, most importantly symptom severity (Ingham and Miller 1986; Hopton et al. 1996), or potential severity (Elliot et al. 2012), and familiarity (Mechanic 1962), but also including the individual’s social bonds and networks (Zola 1973; McKinlay 1973), previous experiences of health service use (Hannay 1979; Cornwell 1984; Hopton et al. 1996), access to services (Dixon-Woods et al. 2005), the organisation of the health care system (Blaxter and Paterson 1982; Campbell and Roland 1996) and the availability of relevant information about choices, including information based on other peoples’ personal experiences (Entwistle et al. 2011). The decision that something is an illness and that it is serious enough to require professional attention is rarely made lightly (Blaxter and Paterson 1982; Wyke et al. 1991; Houston and Pickering 2000) and may be taken following consultation with others in a person’s social network (Freidson

1960; Zola 1973; McKinlay 1973; Cornford and Cornford 1999), including online networks (Doyle 2013).

Parents, particularly mothers, have been found to be adept at monitoring their children's health and dealing with symptoms (Cunningham-Burley and Maclean 1991). Mothers accept some symptoms or illness as normal for children and determine the level of seriousness based on ideas of what is normal for their child or on the basis of behavioural change (Cunningham-Burley 1990; Cunningham-Burley and Maclean 1991; Wyke et al. 1991). Symptoms considered to be of particular concern to parents largely fall into the categories of respiratory symptoms, fever, vomiting and pain (Neill 2000). Most parents' usual response to symptoms is to care for their child themselves and to use over-the-counter medicines (Cunningham-Burley and Irvine 1987). Help-seeking from the professional sector when children are unwell is only undertaken if symptoms have not responded to home treatment or have worsened (Cunningham-Burley and Irvine 1987), if symptoms are unfamiliar or abnormal for a particular child (Cunningham-Burley and Maclean 1991), or if parents feel unable to cope without professional advice and reassurance (Kai 1996; Hugenholtz et al. 2009). Blaxter and Paterson (1982: 57) found that combinations of symptoms, the time of year and the child's age affected decisions to consult, and there was a 'tendency to worry more and seek advice more quickly for babies' symptoms'. When they decide to seek help, parents are likely to choose the route least likely to expose them to criticism (Neill et al. 2013).

Hannay (1979) identified an 'iceberg' of symptoms in the community, with only a small percentage brought to the attention of medical professionals and most being dealt with in the popular sector. Importantly, he found that about 7 per cent of those who had symptoms for which they did not seek professional help also consulted about what he refers to as 'medical trivia', suggesting that for some people there is no simple pattern of illness behaviour and that any one individual may behave differently depending on the symptoms involved (Hannay 1979: 95). Hannay found that contact with services depends partly on ease of access but that use of services is also affected by how people perceive professionals and facilities and by previous experiences of doctors and hospitals. Those whose previous experiences had been

poor were more likely to consult about ‘trivial’ symptoms, suggesting that ‘the perception of medical services was the result rather than the cause of referral behaviour’ (Hannay 1979: 105). Only one large-scale study has investigated the symptom iceberg in the UK since the introduction of changes to the organisation of primary care and the policy emphasis on the promotion of self-care (Elliot et al. 2011; McAteer et al. 2011). This study found that just under half of reported symptoms resulted in no action, while 35 per cent resulted in self-care, including use of over-the-counter medicines. GPs were consulted for 8 per cent of symptom episodes and the level of use of NHS 24/ NHS Direct was less than 3 per cent (Elliot et al. 2011). This survey reaffirms that the majority of symptoms are still dealt with in the popular sector, in spite of previously noted concerns about rising demand for formal services.

Symptom management within the popular sector may involve doing nothing or engaging in practices of self-care. As noted in section 2.2.1 above, a range of activities come under the heading of self-care, including health behaviours such as maintaining a healthy diet and exercise as well as actions taken to treat symptoms or manage chronic illness. Wilkinson and Whitehead (2009) reviewed work on the concept of self-care and found that there is no consistent definition in the literature and there is also confusion around the sometimes interchangeable use of the term self-management. There is some dispute in the literature about whether there is a continuum of self-care which can include supported self-care or shared care, or whether self-care is solely that which does not involve a health professional (Chapple and Rogers 1999). For example, in her study of telecare practices, Pols (2012) problematises the ideas of ‘self’, ‘care’ and ‘self-care’. She argues that ‘patients never care for themselves alone but rather the work of ‘caring for the self’ is always ‘distributed among patients, professionals, devices and others’ (2012: 76). Pols’ analysis suggests that both professionals and technology can be a part of what might be defined as ‘self-care’ and that the terms ‘self-care’ and ‘self-management’ fail to take account of these interdependencies. One issue on which there does seem to be agreement, however, is that self-care is increasingly medicalised and that self-care information ‘often reflects medical norms and values’ (Segall and Goldstein 1989:

160). In fact, Conrad (2007: 11) has suggested that ‘much of what is called self-care involves the use of medical approaches by lay people in the absence of professional medical treatment’.

Porteous et al. (2007) used a discrete choice experiment to measure people’s relative preferences for managing ‘flu-like symptoms’ and the relative importance of waiting time and costs in influencing their decisions. They found that people preferred to do something about symptoms rather than doing nothing and that self-care was the preferred management option, followed by pharmacy advice or GP consultation. Seeking advice from NHS 24 was preferred significantly less and, while the reasons for this cannot be identified from the study, the authors suggest that there may have been a lack of experience of NHS 24 amongst the respondents, they may have considered it to be inappropriate for the symptoms described, or the adverse publicity surrounding the service at the time of the research may have had an effect. One important limitation to this study is that the symptom scenario described to participants was straightforward, uncomplicated and, of course, hypothetical (as acknowledged by the authors). In reality, decision-making about how to respond to symptoms is influenced by numerous factors other than symptomatic ones, as highlighted above, and while people may present themselves as willing to self-care, the complexities of real-life illness scenarios sometimes lead to consultation even for seemingly minor symptoms (Cantrill et al. 2006).

As with self-care, there is no universally accepted definition of help-seeking. It can be interpreted to mean looking for *any* form of help, including within the popular sector, or it can be used solely to mean seeking professional advice. Rogers et al. (1999) highlight the problem of conflating ‘help-seeking’ with ‘health service use’, without accounting for the fact that services in the professional sector do not represent all available sources of help. Nevertheless, in much of the literature on illness behaviour, help-seeking refers to seeking advice from a healthcare professional. Dixon-Woods et al. (2005: 47) note that ‘help-seeking behaviour is strongly influenced by the resources available to people’ and also relies on individuals having the knowledge and capacity to both ‘identify and evaluate their symptoms’ and to ‘negotiate routes to health care’. Help-seeking may be preceded by

self-care and self-monitoring and it may be the failure of self-care to work fully or quickly enough, along with fears that self-diagnosis may have been incorrect and the problem may be more serious than initially presumed, that leads to a consultation (Leydon et al. 2009).

Research on help-seeking out-of-hours has found that, although symptoms are described as the main reason for calling a GP in the out-of-hours period, a range of other factors influence people's decisions to seek help (Hopton et al. 1996). These include worries about specific illnesses such as meningitis or appendicitis, the failure of attempts to manage the problem through self-care or previous help-seeking or a sense of responsibility towards others. Previous experiences of health services and health professionals are also significant, and 'past frights' in which illnesses had been more serious than expected led people to be more risk-averse in their decision-making. Interestingly, this research found that 'both positive and negative experiences were used to explain the importance of seeking formal help' and that some experiences of health care can 'disrupt confidence in self-management and fail to allay concerns, even increasing them' (Hopton et al. 1996: 994). Houston and Pickering (2000) explored parents' use of out-of-hours primary care for children and found that parents usually took considerable measures to manage their child's illness at home, did not make the decision to call the doctor lightly and worried about being seen as unable to cope or wasting the doctor's time. However, they also lacked confidence in their own abilities and worried about doing the wrong thing.

Research on use of out-of-hours care in Glasgow prior to the introduction of NHS 24 (Drummond et al. 2000: 463) found that reasons for contact were related to 'the perceived urgency of the problem and perceived difficulties with daytime services' including GP access. Reasons for consultation were also associated with socioeconomic factors: 'perceived urgency' was significantly higher for adults and the elderly, while 'perceived difficulties with daytime service' was associated with 'adults, males, the non-affluent, and those presenting with musculoskeletal problems' (Drummond et al. 2000: 463). Males showed a preference for using the out-of-hours service unrelated to their perception of urgency. The authors suggest that perceived difficulties with daytime access amongst the non-affluent may be because they are

less likely to work in roles that allow freedom to visit a GP during the day without loss of earnings. The authors also suggest that the availability of a dedicated out-of-hours service could encourage help-seeking out-of-hours rather than in-hours ‘since by its existence it legitimises help-seeking’ (Drummond et al. 2000: 463).

In this thesis I have chosen to use self-care to mean activities which take place in the popular sector of the health care system, including self-medication (or medication of children), lay consultation and seeking information in books or online. I use the term help-seeking to refer to seeking advice from within the professional sector, including from pharmacies and NHS 24. Of course, acknowledging the conceptual issues I have outlined here, I recognise that looking for information on a website such as NHS Inform, asking a pharmacist to advise on medication, or asking NHS 24 for advice about treating symptoms at home are all activities that occur at the boundary of the popular and professional sectors and could be interpreted either as self-care or as help-seeking. This is something that I will explore further in my analysis and discussion.

2.3.2 ‘Appropriate’ help-seeking

There is often a very strong moral aspect to discourses of health, illness and help-seeking (Zola 1972; Dingwall 1976; Locker 1981; Cornwell 1984; Lupton 2012) and those who claim illness are frequently constructed by others in moralistic terms based on the attribution of responsibility and blame. For example, Cornwell (1984) notes the importance of self-presentation as healthy and the stigma of ‘hypochondria’ amongst her participants; ‘stoics’ were lauded while those considered to be hypochondriacs were ostracised. In particular, decisions about children’s health and illness are morally charged, as highlighted by Prout (1986) who shows how maternal competence is judged on the basis of mothers’ responses to their children’s symptoms. Neill et al. (2013: 765) even argue that ‘the desire to avoid felt or enacted criticism is the primary motivator for parents’ decision-making in response to a child’s acute illness, apart from the obvious concern for the child’s health’.

Zola (1972: 490) suggests that some of the stigma historically attached to sickness has been displaced, so that while ‘individuals are no longer directly condemned for

being sick', their moral character is now assessed based on what they do about it. Seeking help too quickly or delaying for too long can both result in criticism and in accusations of either 'neglect' or 'consultation for trivialities' (Blaxter and Paterson 1982: 64) meaning that people must strike a balance to avoid being labelled as either a time-waster or as 'obtuse for non-attendance in the presence of potentially serious symptoms' (Adamson et al. 2009). The need for people to protect their identity as rational and responsible users of health-services, not to waste resources and not to be a burden on anyone can lead to delays in help-seeking (Kai 1996; Houston and Pickering 2000), including in cases of potentially serious illness (Pattenden et al. 2002).

Media reports of a service under pressure, or even in crisis, may sensitise people to demands on resources and professional time and increase anxieties about help-seeking (Goode et al. 2004a; Dixon-Woods et al. 2005; O'Cathain et al. 2005; Hillman 2014). The experience of modern life has been described as 'mediated' (Giddens 1991) and media discourses shape our knowledge, understandings, experiences, practices and interactions around health, illness and medical issues (Williams and Calnan 1996a; Lupton 1998; Seale 2003). The UK media regularly run stories about the pressures faced by health services, with headlines such as 'Why GP surgeries need crowd control' (Martin and Dunbar-Rees 2012), 'Warning over struggling GP system' (Triggle 2013b) and 'Ambulance 999 timewasters risk lives' (BBC News 2014). Accusatory articles appear in which the public are berated for using emergency departments 'like McDonalds' (Gyford 2011) and asking people to 'think twice' before seeking emergency treatment for minor illnesses (BBC News 2011). Sometimes this is framed as an 'appeal' to the public not to attend A&E unless they are facing 'a genuine emergency' (Wilson 2011), or to use the ambulance service 'sensibly' (BBC News 2013), reinforcing the idea that health services are in crisis and that it is the responsibility of individuals to mitigate the problem through appropriate behaviour. This sort of media attention arguably serves to generate public condemnation of the misuse of services and therefore public legitimisation of forms of rationing which prioritise those who are considered most deserving.

The issue of ‘inappropriate’ use of health services has generated research aimed to understand perceptions of ‘appropriateness’ from the perspective of both service users (Sanders 2000; Adamson et al. 2009) and professionals (Sanders 2000; Smith et al. 2001). The issue has been of such interest in work on emergency care that helpful keywords for searching medical and nursing literature on use of emergency departments include ‘misuse’, ‘abuse’ and ‘inappropriate’ (Roberts 1992: 111). Timmons and Nairn (2015: 6) suggest that the problem of inappropriate use is one which is policy driven, ‘both from a professional perspective as an attempt to exclude what is deemed trivial and from a management perspective that regards such patients as financially wasteful’. Similarly, Klein (2010: 177) argues that the rhetoric of appropriate treatment and care can be seen as emerging, in part, in the policy context of rationing:

[...] political decisions about the allocation of resources were translated into clinical decisions about which patients should get treated and how. Ministers and managers were able to shelter behind the doctrine of clinical judgement. The care that patients received (or did not receive) was presented to them as reflecting their doctor’s assessment of the appropriateness of particular interventions rather than the scarcity of resources. Doctors, in turn, internalised scarcity in their judgements about appropriateness.

From a professional perspective, definitions of appropriateness are multi-dimensional and are based on, for example, the severity or potential severity of symptoms, the ‘genuineness’ of the illness, patient characteristics and patient attitudes (Smith et al. 2001). Clinicians may construct a ‘hierarchy of appropriateness’ which reflects their own interests, including the level of expertise needed to deal with the problems patients present with, so that ‘those patients requiring the most expertise are the most valued’ (Charles-Jones et al. 2003: 75). Definitions of inappropriateness are based on an even more diverse array of factors, including the timing of help-seeking, perceptions of patient’s motivations and expectations, and perceptions that the patient is unreasonable or irresponsible (Smith et al. 2001). Explorations of the concept from a lay perspective (Cross et al. 2005; Adamson et al. 2009) find more contingent understandings of appropriateness and a general reluctance to make definitive statements about what is or is not appropriate. As Goode et al. (2004a: 215) report:

Our callers' accounts of using the wider NHS reveal that they are [...] highly reflexive in relation to the risks of being constructed as an 'undeserving' patient or a 'time-waster' and of not simply 'consuming' services, but of 'being demanding' in 'inappropriate' ways. Our interviews suggest that both professionals and the public share a vocabulary of 'appropriate' and 'inappropriate' use of services, but that professionals use it without defining what these terms mean while the lay public has appropriated the terminology, only to struggle with working out its meaning in practice.

Appropriateness of demand is negotiated at the boundaries between primary and secondary care, between different medical specialties and between providers and users (Rogers et al. 1999). Definitions of what is appropriate are generally made from a professional perspective, but Hillman (2014) shows how the appropriateness and legitimacy of help-seeking can be constantly negotiated in interactions between patients and staff. Patients can use 'strategies of negotiation' to 'avoid a charge of deviance and pass as legitimate' (Hillman 2014: 495) and their success in presenting their claims to care as legitimate shapes their access to and experience of care. In the context of NHS Direct, Goode et al. (2004a: 225) found that 'callers attempts to demonstrate "nursability" were apparently met with messages that "that's what we're here for", explicit reassurance that their concerns were not trivial or inappropriate [and] encouragement to call again whenever they felt it necessary'. The authors conclude that NHS Direct seemed to legitimise demand and dispel fears of inappropriateness; however, they cautioned that increasing demand for the service could change this.

What is understood by appropriateness is context-dependent (Bezzina et al. 2005), can change over time and varies between individuals or between groups of professionals. In Cook et al.'s (2010) study on the appropriateness of NHS 24 referrals to an emergency department, the authors found that 'a large proportion of primary care patients are being handled inappropriately and uneconomically in the ED setting' (2010: 215) but there was a statistically significant discrepancy between the number of referrals that emergency medicine consultants thought should be handled in the emergency department and the number of referrals that GPs thought were suitable for emergency department care. Interestingly, the consultants thought that more cases should be handled in their department. Equally, the GPs thought that

more cases could have been handled in primary care. On the basis that the concept of inappropriate demand is so contingent, its usefulness has been contested (Chew-Graham et al. 2004) and less judgemental terms such as ‘incongruous’ (Elliot et al. 2012) or ‘ineffective’ (Davies and Fazey 2014) help-seeking have been proposed. It has also been suggested that it is services, rather than patient behaviours, that are inappropriate (Chew-Graham et al. 2004; Bezzina et al. 2005) and that services should be organised to meet the needs expressed by the public (Snooks et al. 1998) rather than in response to professional attitudes or agendas (Sanders 2000).

Appropriate use of health services has been the focus of several media campaigns and educational interventions aimed at the public, for example NHS Scotland’s ‘Know Who To Turn To’ campaign. This campaign, based on the similar ‘Choose Well’ campaign in England and Wales, was originally piloted in Grampian with funding provided by the Scottish Government. The campaign aimed ‘to raise awareness of the Unscheduled Care Services available in NHS Grampian and educate the public on which services to use and when’ with a view to ‘reducing inappropriate referrals’ (The Leith Agency 2009: 3). Pre-campaign research suggested that barriers to the ‘correct’ use of services included lack of transport, lack of access to other services (not enough staff or appointment times), lack of knowledge about where to go and in what circumstances, and a perception that people would be seen more quickly at A&E than if they waited for a GP (The Leith Agency 2009: 5). The report on the pilot recognised that education alone will not change behaviour until actual and perceived barriers to appropriate service use were addressed (The Leith Agency 2009). Nevertheless, in spite of limited evidence of its efficacy (Audit Scotland 2010), the Scottish Government funded the roll out of ‘Know Who To Turn To’ in every health board area and a centralised website, launched in April 2014, is now hosted by NHS 24 (www.knowwhototurnto.org).

Underlying such ‘procedures of motivation’ (Rose 1999: 8) is the notion that if patients are educated in the ‘appropriate’ use of services, they will alter their conduct to align with the aims of service providers. Dixon-Woods et al. (2005: 79) reviewed research into educational interventions as a means of influencing service use and found that the intention underlying many of them is to ‘correct people’s

misunderstandings about illness' in order to reduce 'inappropriate' consultations, 'particularly for minor illness and particularly for children'. This is based on an 'information deficit model' (Heaney et al. 2001) which sees increasing demand for health services as a result of people's lack of knowledge about how to look after themselves and how to use health services. However, it has been argued that such an approach is too simplistic given the complexity of decisions about help-seeking in which 'biomedically "correct" information' is just one resource that people draw on (Dixon-Woods et al. 2005: 79). A more 'contingent model' (Heaney et al. 2001) seems to be supported by evidence of the limited impact of educational interventions aimed to improve self-efficacy and reduce service use for minor illnesses (Heaney et al. 2001; Little et al. 2001). Milewa et al. (2000) suggest that the reason for this limited impact is that such interventions are based on a form of instrumental rationality which supposes straightforward cause and effect, without taking account of the reflexive ways in which individuals engage with expert advice. Hopton et al. (1996: 991), in noting the importance of a wide range of influencing factors on decisions to seek help, conclude that attempts to educate and encourage people to use services appropriately while neglecting individual context 'may be too simplistic'. Similarly, Cornally and McCarthy (2011: 286) argue that interventions focussed on knowledge and awareness 'only have moderate effect' because they 'only work on one aspect of the help-seeking process, that is, problem recognition and definition' without taking into account the other factors which impact on the decision to act and the selection of the source of help.

The need to use services appropriately means that as well as interpreting problems as symptoms and deciding that help is required, people must engage in further interpretive work in order to determine which service to approach for this help. In doing so, people must negotiate morally appropriate behaviour, the needs of the health service and the embodied experience of illness in deciding what is the 'right' thing to do. The sorts of education campaigns described above rely on people understanding and being able to operationalise a range of different descriptors for the level of seriousness of a symptom, illness or injury. The next section explores this idea further.

2.3.3 Assessing and categorising symptoms

As noted above, decisions about when and where to seek help begin with the interpretation of a problematic experience as being due to a biological cause (Locker 1981; Leder 1990; Jutel 2011a). Once a problem has been identified as an illness, the interpretive process continues to determine what type of illness it is and whether or not it is serious enough to require medical help. Perceived seriousness of symptoms is a major determinant of help-seeking from the professional sector (Mechanic 1966; Hannay 1979; Lydeard and Jones 1989; Hopton et al. 1996) but research on how patients perceive urgency is remarkably limited. Campbell (1999) has found that socio-economic deprivation is associated with a heightened sense of medical urgency and Hugenholtz et al. (2009) found that parents defined symptoms as urgent at the point at which they felt in need of immediate professional advice.

‘Appropriate’ help-seeking depends on choosing the right service for the severity of the illness. The ‘Know Who To Turn To’ website (image 2) provides a useful illustration of the way that symptoms must be accurately categorised according to urgency. The design, in which services are represented by boxes, could be interpreted as suggesting that correct service use is as straightforward as selecting the right box.



Image 2: www.knowwhototurnto.org homepage (accessed March 2015)

Image 2 shows how, in deciding what to do about symptoms, a decision must be made as to whether the illness is ‘minor’, ‘urgent’ or should be considered an ‘emergency’. It also demonstrates that these categories can overlap, as the minor injuries unit is described as being for ‘urgent care’.

Terms such as minor, urgent and emergency are not well-defined and can be employed to serve the specific purposes of those using them. For example, the Proprietary Association of Great Britain defines minor ailments as ‘conditions which do not pose a major health risk and can be managed with non-prescription medication bought from a pharmacy or supermarket’ (Banks 2010: 3) reflecting their specific interest in medication use. Cantrill et al. (2006) show how the ways in which people classify minor ailments are contingent. In their study of how patients make decisions to consult a GP about minor illnesses, they found that ‘previous experience and personal knowledge of an illness was key in the interviewees’ decision to classify an illness episode as a minor ailment’ (2006: 160). People were most likely to classify an illness as minor if they knew what the condition was and how to treat it themselves based on their own experience, the experience of others, or from professional advice received on a previous occasion. Conditions that might have been serious from a clinical perspective could be considered minor as long as people knew how to deal with them, whereas lack of knowledge or experience introduced an element of doubt and could lead to the need for a GP consultation. Importantly, conditions could change from major to minor, and vice-versa. As a result, the authors conclude that ‘it is not always helpful to think of specific conditions as being minor or major’ as the terms are constructed differently depending on the context (Cantrill et al. 2006: 163).

At the other end of the spectrum, the concept of the ‘emergency’ is also ill-defined, although it has been given considerable attention because it is linked to professional boundaries and occupational prestige (Roberts 1992; Timmons and Nairn 2015) and is key to discussions of the appropriate use of emergency services. In Scotland, there is no agreed national definition of what constitutes an emergency and the terminology used differs amongst services (Audit Scotland 2010). What is considered to be an emergency depends on perspective, for example professionals in

all fields deal routinely with situations that are emergencies to the individuals who experience them (Hughes 1971). As Timmons and Nairn (2015: 5) point out:

The emergency requires the mobilisation of extra effort and resources. But what constitutes extra effort and resources depends on which side of the professional/lay divide one happens to be. The emergency is, therefore, a negotiated reality between people and not an objective description of reality.

Literature on how the urgency of patient need is categorised by medical staff, for example in the process of triage, shows that it is also a subjective process for clinicians and ‘challenges the assumption that the ordering of patients into categories of priority is solely a clinical endeavour’ (Hillman 2014: 485). Work such as that of Jeffery (1979) shows that while ‘good’ patients may be categorised according to their clinical presentation, ‘rubbish’ patients are categorised on the basis of perceived moral worth, responsibility and conformity to the sick role. Patients are also categorised ‘according to the professional interests of clinicians and the broader organisational structures and institutional cultures of clinical practice’ (Hillman 2014: 486).

The ability to assess and interpret symptoms has long been considered to be the preserve of clinical professions and the means by which they establish their authority (Freidson 1970; Jutel 2011b; Jenkins 2014). However, it has been suggested that diagnosis is ‘a ubiquitous and everyday activity for us all’ (Dew and Jutel 2014: 74) as most of us shape our thinking about illness in diagnostic terms and may use medical diagnostic techniques to interpret symptoms as a matter of routine. For example in research by Hugenholtz et al. (2009: 175):

...many parents performed diagnostic procedures on their children before contacting immediate-care services. As well as taking their temperature – the procedure mentioned most frequently – parents had checked for neck stiffness, examined the throat, palpated the abdomen, tested the eyes of their children, searched for bruising, and palpated the fontanelles.

In some circumstances, lay or self-diagnosis is legitimated and even encouraged, for example in direct-to-consumer advertising of pharmaceuticals or in the management of public health threats (Jutel 2011a). During a H1N1 flu pandemic in 2009, public health messages designed to control infection asked people to stay at home if they

had the flu and only to seek help if they experienced complications. This call for widespread self-diagnosis presumed that individuals could distinguish the symptoms of flu from other illnesses such as colds, pneumonia, sepsis or meningitis. However, neither lay people nor health care workers are very good at self-diagnosis of flu (Jutel et al. 2011). During the first month of the same outbreak of H1N1 influenza, NHS Direct received approximately 63,000 calls relating to swine flu, although over the same period only 185 cases of swine flu were confirmed in the UK (Rubin et al. 2010). Reasons for seeking advice from the helpline included the severity or unfamiliarity of symptoms, concerns about exposure to and transmission of infection, pressure from others and a need for reassurance. This shows the extent to which people felt uncertain about the meaning and urgency of their symptoms, unable to accurately diagnose themselves, and reliant on expert advice to assess the best course of action.

Risk

People must determine the urgency of symptoms in the context of the increased awareness of danger that characterises the ‘risk society’ (Giddens 1991; Beck 1992). The term ‘risk’ does not have consistent meaning throughout the literature or across disciplines; however, what most usages have in common is the idea of ‘potentiality’ (Rigakos and Law 2009) or the possibility that something will happen which can be avoided by taking action (Zinn 2008). Risk is most usually evoked to describe dangers such as ‘the threat of nuclear warfare and ecological catastrophe’ or, at a more individual level, the hazards of ‘modern medical technology, coronary heart disease and “unsafe” sexual contact’ (Williams & Calnan 1996: 1614). The concept of risk has been explored in previous work on NHS Direct (Goode et al. 2004a; Hanlon et al. 2005) and in the context of NHS 24 from the perspective of nurses (O’Cathain et al. 2007), but it is rarely applied to everyday decision-making about acute symptoms which could be either minor or serious. Risk, in the sense that I use it in this thesis (particularly in chapter 5), has only previously been applied to the context of help-seeking out-of-hours in one study that I am aware of (Hugenholtz et al. 2009).

Hugenholtz et al. (2009: 178) note that although studies have shown that ‘worry’ is an important determinant of parents’ decisions to consult about their children, ‘this worry has so far not been related to the preoccupation with risk that pervades health care, and the central role of risk regulation in society as a whole’. Their study found that most consultations were triggered by a need to rule out or prevent serious illness rather than as a result of the symptoms themselves. Also, not only did parents monitor their children’s symptoms, but they engaged in reflexive monitoring of their own feelings about the situation, which influenced their decisions to seek help. The authors propose that parents’ help-seeking out-of-hours can be interpreted as behaviour that is ‘typical for the “risk society”’ and, although parents may seem irrational, ‘their behaviour might be in line with the societal trend towards risk aversion’ (2009: 174). Interestingly, this study found that reassurance and the elimination of risk was more important than treatment:

Relief of complaints, one of the traditional reasons for seeing the doctor, does not seem to play an important role in the motivation of these parents: they want to rule out risks. Parents relate their fears to life-threatening conditions that can develop in a short time span, such as meningitis and appendicitis. Overall, parents ask for immediate care when they are afraid of a serious disease. They seek prevention, diagnosis, and reassurance. Treatment and cure are secondary to them when using out-of-hours services. Parents principally try to regulate their own risk perception. In this sense, the concept of a ‘risk culture’ could be applied here (Hugenholtz et al. 2009: 177).

Other research has shown that what parents worry about most when their children are ill is that they might fail to recognise a serious problem (Kai 1996; Walsh et al. 2007) which could lead to death or permanent harm (Cornford et al. 1993; Kai 1996). The possibility of meningitis was one of Kai’s respondents’ primary concerns and amongst his participants ‘there was a common understanding that symptoms could be non-specific and the illness rapidly overwhelming, heightening anxiety about not detecting the disease’ (1996: 985). For this reason, ‘any unexplained rash could herald immediate danger and the need to seek medical advice’ (1996: 985).

Experiential knowledge of symptoms and illness can influence perceptions of risk, particularly where symptoms have previously been dismissed as trivial but turned out to be serious (Hopton et al. 1996). This was exemplified by the mothers in Blaxter

and Paterson's (1982) study; for example, one mother said that she consulted for her 2 year old 'the minute he gets the cold' because she had 'let it go once' and 'he got measles' (1982: 58). Another became extremely worried if her toddler developed a cold, especially with a cough, because she had contracted whooping cough at 3 months: 'I tend to panic and get the doctor in right away- it might turn into something' (1982: 58). The medical history of a particular child or that of other family members may increase anxiety (Blaxter and Paterson 1982; Prout 1986).

In order to be able to assess risk, people must engage with large amounts of technical information, 'much of it potentially contradictory or unclear' which, in the risk society, 'circulates at an ever faster rate, issued from "abstract systems" and produced by increasing numbers of experts' (Gabe and Bury 1996: 74). Some of this information is communicated via popular media; however, the media has also been shown to contribute to 'heightened awareness of risk, danger and uncertainty' (Lupton 1998: 205). For example, in noting the likely effect of media coverage and campaigns about meningitis at the time of his research, Kai (1996: 986) comments that 'the pressure parents experienced may have been intensified by messages such as "knowing the symptoms of meningitis could mean the difference between life and death"'. More recently, a US study found that exposure to media reports about swine flu increased worry about infection (Mesch et al. 2013). There is, therefore, some evidence to suggest that awareness of risks plays a part in people's interpretation of symptoms, particularly for children. However, there is limited research in relation to people's decisions about their own acute symptoms in the context of risk-awareness and there is room for development of the concept as it is used by Hugenholtz et al.

2.4 Summary

This chapter has outlined both well-established and more recent theoretical concepts which form the foundation of the analysis presented in this thesis. It has also provided an overview of the policy drivers for the establishment of NHS 24 and introduced the service in more detail. I have established the position that illness behaviour and health service use can only be understood in the context of the health care system and the choices available to people. I suggest that Kleinman's (1980)

model is a useful heuristic device with which to do this, as it allows for exploration of the spaces where the popular and professional sectors of health care intersect and overlap. Theories of medicalisation and lay-reskilling help to illustrate how the boundaries between the popular and professional sectors are both shifting and permeable and I suggest that this has implications for how we develop an understanding of NHS 24 and its place in the contemporary health care system, particularly given its aim to support practices of self-care.

Although much has previously been written about illness behaviour, most theoretical development has been in relation to chronic illness or the management of specific symptoms. Of the literature that explores how people manage acute symptoms, much of it is dated and much of it deals specifically with parents and children. Gaps remain in relation to how people manage common and self-limiting symptoms and the factors that lead them to seek help (Porteous et al. 2007) and in relation to new forms of service provision such as telephone advice lines (Davies 2003; Wyke 2003). There have been recent calls for research into why people are seeking help out-of-hours, the decision-making process they go through and the beliefs that underpin these decisions (BMA Scotland 2010; 2012). Although there has been some qualitative research with callers to NHS Direct in England, to date there is no published work which explores the perspectives of callers to NHS 24. Furthermore, the work that has been published on NHS 24 is largely evaluative rather than conceptual.

Illness behaviour and help-seeking decisions are complex and influenced by a broad range of contextual factors. Symptom severity, unfamiliarity and concerns about potential danger can all trigger a consultation but the decision is rarely made lightly and anxieties about being labelled a ‘time-waster’ or a ‘hypochondriac’, especially in light of media reports of a health service in crisis, may make the decision all the more difficult. Once the decision to seek help has been made, a proliferation of routes into care makes negotiation of the health care system complex, especially as the boundaries between organisations and services are not always clear and the boundaries between categories of symptom urgency are not clear either. NHS 24 was established to help people to access the right service to meet their needs, but rising demand has led to attempts to limit use of the service to cases which are considered

to be ‘urgent’, meaning that it can now be understood as one of a number of points of access that people must choose between when seeking help.

Early work on NHS Direct (Goode et al. 2004a; 2004b; Goode and Greatbatch 2005; O’Cathain et al. 2005) sought to explore the idea of the ‘reflexive consumer’ and engaged with issues of self-surveillance, individual responsibility and empowerment in calls to that service. However, this body of work does not explore in depth the specific symptoms and circumstances that led people to call for help. More recent work has suggested that decisions to seek help out-of-hours can usefully be understood in the context of the ‘risk society’ (Hugenholtz et al. 2009). This application of the concept of risk has not been further developed and there is room to explore the place of discourses of risk, responsibility and the use of knowledge in how people account for their decisions to call NHS 24.

3. Methodology

This chapter describes how I designed and carried out my research and the rationale for the decisions I made about research design, data collection and analysis. The data which informs this thesis was collected in 3 phases. The first and second were a 6 week period of observational fieldwork followed by a series of 6 focus groups; these will be discussed briefly as part of the process of designing the main study. The main phase of data collection involved carrying out 30 in-depth interviews with people who had called NHS 24. Image 3 below shows how the phases of the research were interlinked.

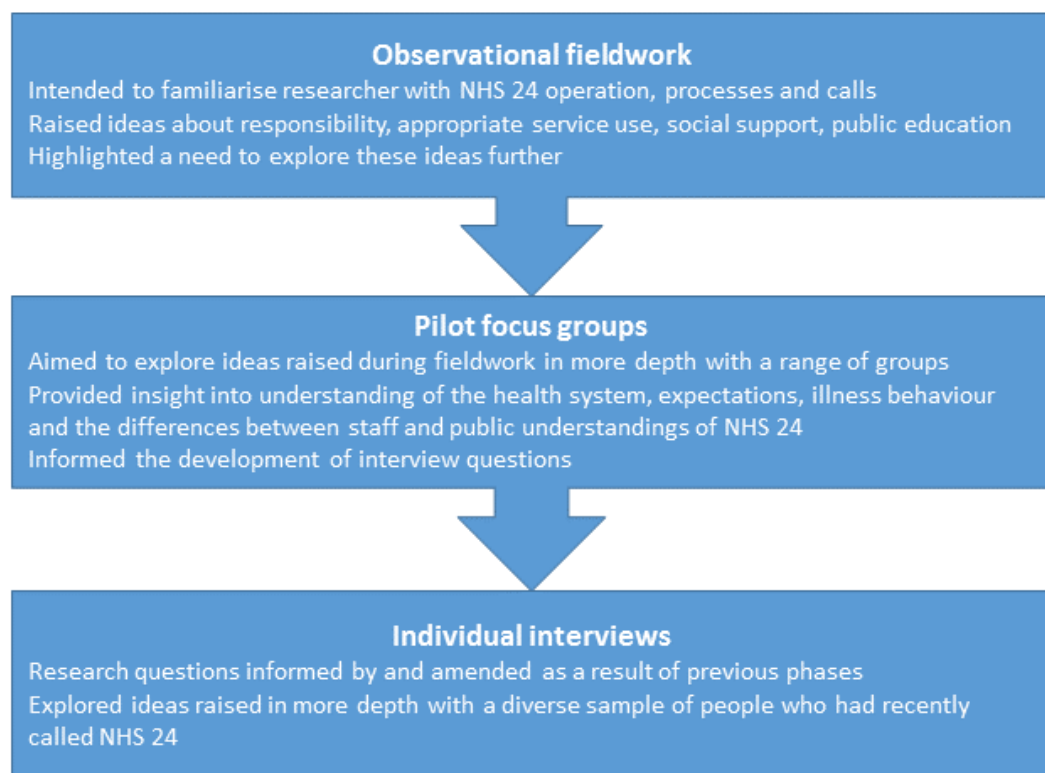


Image 3: Flow chart depicting the phases of the research

In this chapter I discuss how the sample was chosen and recruited and I introduce the interviewees. I consider some of the challenges involved in conducting the research and reflect on what I have learned in meeting these challenges. I also reflect on how my position as researcher has influenced the process of this research, the nature of the accounts and the analysis.

3.1 Research design

This research has been informed by the perspective of empirical phenomenology (Aspers 2009) which aims to understand social systems and processes from the point of view of those who experience them. This approach emphasises that meaning can only be understood when it is based on the ‘first-order’ or ‘common-sense’ constructs (Schutz 1962) of individual actors. Additionally, I have been influenced by social constructionism (Berger and Luckman 1967), which is rooted in phenomenology, in my exploration and questioning of some of the taken for granted ideas which have come to dominate both public and health policy discourse on illness behaviour and health service use. Finally, my approach has also been informed by structuration theory (Giddens 1984), insofar as I have incorporated the idea that social systems, processes and institutions both influence and are influenced (reproduced) by the ideas and actions of the individuals who interact with them. In this research, I aimed to understand participants’ illness behaviour and the meanings they attribute to it in their own terms. I also aimed to explore how people’s understandings of NHS 24 might influence how and when they use it and how their use of NHS 24 might in turn influence the way in which the service is delivered.

Empirical phenomenology requires interaction with the individuals who are the subject of the research (Aspers 2009). In particular, the approach outlined by Aspers includes a combination of observation in the field and interviews with those who are to be studied. Qualitative methods are particularly useful in studying context (Barbour 2008) and in ‘exploring social actors’ meanings and interpretations’ (Blaikie 2009: 204-5). The methods of observation, focus groups and interviewing chosen for this research project allowed the exploration of a diversity of experiences and perspectives which would not have been easily identifiable through, for example, the use of surveys or analysis of statistical data.

The type of information that was already available about callers to NHS 24 was not suitable to answer my research questions. Statistical reports on a wide range of data are produced regularly by NHS 24. However, these are primarily designed for performance reporting and service planning. They convey information about ‘Key

Performance Indicators’ such as the length of time people wait for their call to be answered, rather than detailed socio-demographic information. ‘Call trends’ are also reported on a weekly basis, showing a breakdown of calls by final disposition and also by the main algorithm used in the call. These trends are aggregated into very broad categories such as the age and sex of the patient. These reports show some patterns, but what they can tell us about who is calling NHS 24, and why, is quite limited. Regular patient experience surveys are also carried out by NHS 24; however, these are large-scale standardised questionnaires designed to evaluate people’s experiences of using the service. While these surveys provide valuable background knowledge, they do not allow an in-depth understanding of people’s use of NHS 24 at the individual level or how they negotiate decisions about symptoms and health care use.

3.1.1 Exploring NHS 24

The aim of this research was to explore the illness behaviour of callers to NHS 24 but my first task was to find out more about NHS 24 itself in order to understand the structural and organisational context in which individual interactions take place. Early in the project I completed a 6 week programme of induction and observation intended to familiarise myself further with NHS 24 and provide context for the research. This included meetings with key personnel and periods of observation in NHS 24 call centres speaking to staff and listening to calls. I spent time with all NHS 24 ‘skillsets’ and also with the Scottish Ambulance Service (SAS) and in a Primary Care Emergency Centre. During this time I learned more about how the organisation works, gained an understanding of the patient journey and spoke to a wide range of staff from across the organisation, both frontline and management. This period of observation was informal; it was not conceived as part of the research and did not have ethical approval. Therefore, although I kept detailed notes, they do not form part of the data presented in this thesis. Rather, they provided me with rich contextual information and helped me to identify key issues for the subsequent interview study.

Many recurring themes emerged during the course of my observational fieldwork which led to the development of the eventual study design. In particular, I was interested in the ideas expressed by the staff I spoke to about who uses NHS 24 and why. Some talked about what they perceive as callers' inability or reluctance to self-care or to 'take responsibility' for themselves and their own health. They also spoke about both the public and other professionals having unrealistic expectations of what NHS 24 could provide, which they often linked to a lack of education about 'appropriate' routes for seeking health care or advice. Some people I spoke to felt that social change, particularly more fragmented and dispersed families, has led to greater reliance on health services as people are lacking 'traditional' social support. I heard the words 'appropriate' and 'inappropriate' used frequently, to describe calls, callers, call streaming and call outcomes and I began to wonder about the meanings these words hold and the actions they came to be associated with. I found great support amongst the staff for my proposed research, as it seemed that the questions I was asking were questions that they themselves were seeking answers to.

I listened to calls made to both NHS 24 and the SAS and noted that there was some crossover between the types of calls made to each service. NHS 24 received some calls which required an emergency ambulance response and the SAS received a number of calls which were suitable for assessment by NHS 24. NHS 24 also received calls which would be suitable for a routine GP appointment. This highlighted that the decision about which service to contact is not based on a straightforward categorisation of symptoms understood by all callers. The staff I spoke to had strong views on this; some suggested that people will call or attend the service that is most convenient for them, rather than the most appropriate for their needs. Again, this was attributed to a lack of education and in some cases to attempts to 'play the system' or bypass gatekeepers in order to get care more quickly. It was also suggested that some callers use NHS 24 as an alternative to their GP because it is more convenient to be seen out-of-hours rather than having to take time off work. This behaviour was widely criticised but, at the same time, the way that NHS 24 operates was seen as reinforcing it because callers often can get a much better (faster, more convenient) service from NHS 24 than they would from their own GP practice.

These observations informed my decisions about the study sample and interview design. I was interested in learning more about the reasons why people called out-of-hours about symptoms that did not need immediate attention. Of course, this became the first major challenge in the research design and later one of the key research questions: what symptoms *do* need immediate attention, and how can they be identified by a lay person? I wanted to explore how people categorise symptoms or illnesses as minor or serious, how they make decisions about whether or not they need to seek help from a health service, and how they then decide which health service to contact. I also wanted to understand what factors influence this decision other than the severity of symptoms. How much thought do people give to whether or not they need to seek help? Is there really a lack of education about ‘appropriate’ use of health services? Does that term even mean anything to people and, if so, then what?

3.1.2 The pilot study

Following the observational fieldwork I carried out a pilot study which involved 6 focus groups. The aim of the pilot study was to explore the themes which had been identified during my observations in more detail with a range of different people. Focus groups were chosen as the method for this phase as they allow the researcher to observe how accounts are generated in a social context and also to identify themes which emerge spontaneously in discussions (Finch and Lewis 2003). The intention was that this would inform the development of questions for the interview phase of the study (Morgan 1988).

Although I wanted to keep the tone quite conversational, I used a topic guide (appendix 1) in order to focus the discussion and to ensure that all of the topics I wanted to explore were introduced (Barbour 2008). I also prepared 2 vignettes to use as stimulus materials; these were not needed and were not used in the groups. Each focus group lasted between 45 minutes and 1 hour and was audio recorded with the permission of participants. Informed consent was obtained from all participants at the beginning of each group (appendices 2 and 3).

The focus groups were carried out between September and November 2011 with a total of 26 participants. Two groups were recruited from NHS 24 staff (n=4 and n=5), one group from the NHS 24 Public Participation Forum (PPF) (n=3), one from the NHS 24 Clinical Governance Public Panel (CGPP) (n=6), one from a group for mothers of young children (n=5) and one from an exercise group for over 65s (n=3). The participant profile of the groups was quite varied and while personal information was not collected, the age range was from approximately 20-70 years, the groups included 7 men and 19 women and there were participants from both clinical and lay backgrounds. The groups were chosen partially due to ease of recruitment and also to allow for a range of viewpoints to be explored; they were not intended to be statistically or theoretically representative of a wider population.

The 2 staff groups were randomly selected from a list of names provided by NHS 24 of staff on shift at the times the groups were to take place. A total of 17 staff, including nurses, call handlers and pharmacists were invited to take part and 9 chose to do so, 1 man and 8 women, representing a mix of the 3 skillsets.

The PPF and the CGPP were approached as they are pre-existing groups of people with diverse backgrounds (both lay and clinical) who share an interest in NHS 24 and they were easily accessible. The PPF is a group of up to 20 members of the public who are interested in influencing the development of NHS 24 projects and services. The CGPP is a group of up to 9 members of the public who are involved with NHS 24's delivery of the Healthcare Quality Strategy, the Patient Experience Programme and the Scottish Patient Safety Programme. Both of these groups are made up of members of all ages from across Scotland. All members were invited to participate; 4 men and 2 women from the PPF and 2 men and 1 woman from the CGPP chose to do so.

The group of mothers was recruited from a parent and toddler group in an area of multiple deprivation in central Scotland using a personal contact as an intermediary. All parents in the group were invited to participate and 5 chose to do so. They were all female, although fathers were also invited to join the discussion. The group of over 65-year-olds was recruited from an exercise group in an inner-city area, again

through an intermediary. All members of the group were invited to participate and 3 chose to do so, again all female.

The groups were asked about how they categorise illnesses, for example how they define minor illnesses, and were asked to discuss what actions they take in the case of minor symptoms in themselves and others. I asked them about self-care, self-medication, help-seeking and sources of support and advice. I also explored people's general views about NHS 24 and how they understood the service.

Recordings of the groups were transcribed verbatim and the transcriptions were coded thematically with the aid of NVivo qualitative data analysis software (www.qsrinternational.com). Some themes were prominent and recurring, in particular those of generational and societal change, expectations and understanding of health services and a perceived need for better education about health and health service use. The focus group discussions highlighted the difficulty of framing NHS 24 as a single service for the purposes of research because of the ways that people talked about 'the NHS' as a whole, and showed me how important it would be to understand it instead as part of the wider health care system.

Some data from the focus groups is presented in chapter 4 of this thesis and it is referred to or used occasionally elsewhere but the analysis is based primarily on the interview data. Where a quote is from a focus group participant, this is indicated in brackets after their pseudonym.

3.1.3 Interview design

I used in-depth semi-structured interviews (Mason 2002) to collect the data on which the most substantive part of my analysis is based. The original indicative number of interviews was 60, although it was intended that this would be revisited as data collection progressed. Difficulties with recruitment, discussed below, led to a decision being made to stop after 30 interviews. At this point a wealth of rich and detailed data had been collected and so this did not compromise my ability to meet the overall research aims.

I prepared an interview schedule (Barbour 2008) with questions designed to gauge understandings of NHS 24 as a service, to explore individual use of NHS 24 and to elicit information about people's general attitudes to health and health service use (appendix 4). I carried out 3 pilot interviews with acquaintances who had experience of calling NHS 24 and refined the interview schedule following their feedback. The process of carrying out and analysing the interviews is discussed in more detail in the remainder of this chapter and from this point forward, unless otherwise specified, discussion of the research project refers to the interview phase.

3.1.4 Ethics and safety

Ethical considerations were significant in this project as participants were recruited through NHS 24. This means that although not all of the participants were 'patients', they had to be treated as such in the research design and NHS Research Ethics Committee approval was sought and obtained (appendix 5). Ethical approval was also obtained from the University of Edinburgh Centre for Population Health Sciences Research Ethics Committee.

The primary procedural ethical concern was around access to respondents as this required the use of patient identifiable information (names and addresses). This was managed by NHS 24 advisers obtaining verbal consent from callers to pass their names and addresses to me. As all calls to NHS 24 are recorded, there was an automatic record of this verbal consent. Once callers had opted-in to be contacted, I was given their names and addresses only with no other information about them or the reason for their call. This was done on handwritten sheets which were kept within the secure clinical area in NHS 24 call centres. These sheets were destroyed once I had made initial contact with the callers. The recruitment instructions for staff (appendix 6) clearly asked them to exclude children under 16 and any adults who, in the judgement of the staff member, lacked the capacity to give informed consent. The recruitment procedure is discussed in more detail in section 3.2.2 below.

I developed an information leaflet about the research (appendix 7) which stated that there were no known risks of involvement but emphasised that participation was voluntary and that there would be no repercussions if people decided not to take part.

At the request of the NHS Research Ethics Committee, it also stated that I am not a healthcare worker and could not give any medical advice. Consent was sought at 3 separate points in the research process: the initial verbal consent to share names and addresses given to NHS 24 staff; a consent form which was sent to prospective participants along with the information leaflet and an invitation to take part; and finally verbal and written consent obtained at the beginning of every interview, on the understanding that consent could be withdrawn at any time (appendix 8).

As most of the interviews took place in people's homes, measures were put in place to ensure my own safety. For all of the interviews, I told one person the address I was going to and what time I expected to leave. That person was aware of a specified procedure to follow if they did not hear from me within the expected timescale. I then sent that person a text message to let them know when the interview was concluded and they deleted the participant's address once they received my message. This was in accordance with the Centre for Population Health Sciences 'Health and safety guidance for postgraduate students interviewing the public in their homes on their own' (unpublished document).

Confidentiality is of the utmost importance in any research and all of my data has been handled in accordance with the Data Protection Act 1998 (Social Research Association 2005). Interview recordings and anonymised transcripts are stored on a password protected PC and all information which can be used to identify participants is stored separately in a locked drawer. Pseudonyms have been used throughout this thesis and place names have been removed.

3.2 Sampling and recruitment of participants

I aimed to recruit callers who contacted NHS 24 in the out-of-hours period with a minor illness or injury. This posed challenges in terms of identifying what this actually means, as discussed in chapter 2, and how potential participants could be identified. In discussion with my supervisors and NHS 24 staff, I decided that the most straightforward approach would be to select participants on the basis of their call outcome or 'disposition'. I would include all those whose call outcome was recorded as 'self-care' and would exclude those who were referred on for further

treatment. This was the easiest way to identify non-urgent calls, but I recognise that this relied on the assessment of the staff member closing the call rather than any a priori classification. This definitional problem has been discussed elsewhere by Pillay et al. (2010: 106) who proposed a similar post-hoc definition based on outcomes.

One possible approach to this problem in a primary care setting is to validate the term ‘minor ailment’, by considering the outcome after assessment by a GP: those consultations which lead to no prescription or to the prescription of a product which is analogous to one which is available to be purchased for self-care, can be more reliably assumed to be due to a minor ailment.

This approach to sampling also meant that I would have to rely on frontline staff to approach potential participants. The challenges I encountered as a result of my sampling and recruitment strategy and the impact of this on the final sample are discussed further below.

3.2.1 Sampling

I used purposive sampling (Ritchie et al. 2003; Robson 2011) to identify interview participants. This was in order to ensure a range of perspectives and to allow for some level of comparison across different groups. In purposive sampling, selection of participants is based on ‘the researcher’s judgement as to typicality or interest’ (Robson 2011: 275) and allows for the sample to meet the specific needs of the research. I designed a sampling plan to facilitate what Robson (2011) calls ‘dimensional sampling’ which aims to include participants representing each possible combination of the characteristics which are deemed to be important or of interest. The initial sampling plan for this research, based on a target of 60 interviews, is illustrated below.

	Men		Women	
Age of interviewee	Urban	Rural	Urban	Rural
16-35	5	5	5	5
36-64	5	5	5	5
65+	5	5	5	5

Table 1: Initial sampling plan

The categories included in the sampling plan were informed by both anecdotal claims about what may influence caller behaviour, expressed during the observational fieldwork and focus groups, and existing evidence on use of services. NHS 24 staff, in particular, mentioned that they perceive a difference in the way that men and women use the service. They thought that women are more likely to call for themselves and are also more likely to call on behalf of a partner or child. Certainly, there are more calls *about* females than males (i.e. more female patients) (Elliot et al. 2014), but data about callers is not collected. Staff also thought that NHS 24 is used differently by and for different age groups. They told me that parents tend to call quickly about even minor symptoms in young children, whereas older people tend to attempt self-care first and ‘put up with’ symptoms for longer before seeking advice. Again, data confirms that there are variations in use by age group; a large proportion of calls to NHS 24 are about children under 5 and adults under 35, but fewer are for older people (Elliot et al. 2014). The rationale for including people from both urban and rural populations in the sample was that location and physical access to services were considered by staff and focus group participants to be likely to impact on illness behaviour and, again, research has suggested that NHS 24 is likely to have a different impact and to be used differently in remote and rural communities (Roberts et al. 2009; McKinstry et al. 2009; Elliot et al. 2014).

This sampling plan was never intended to be prescriptive, but I found it useful as a guideline and used it throughout recruitment to identify where there might be gaps in the range of participants. I also added a row to record if participants had called NHS 24 for themselves or on behalf of someone else, as over half of calls to NHS 24 are made by a third party (Elliot et al. 2014). Due to the low response rate during recruitment, I actually included everybody who agreed to be interviewed and so the final sample reflects this. Towards the end of recruitment I asked staff to only collect names and addresses from young men and older people to try to boost participation from those groups; however they are still underrepresented, potentially due to their lower use of the service, unwillingness to participate, or possibly because older people in particular are more likely to be seen rather than given self-care advice. The eventual distribution of participants is shown in the table below.

	Men (10)		Women (20)	
Age of interviewee	Urban	Rural	Urban	Rural
16-35	2	1	5	3
36-64	4	2	9	1
65+	-	1	2	-
Call for self	4	1	13	2
Call for other	2	3	3	2

Table 2: Final sample

A final note on sampling is that while I did not exclude anybody who was eligible to participate, I made no specific efforts to target ‘seldom heard’ groups. I was aware of other research going on or recently concluded within NHS 24 at the time that I was conducting my research which aimed to identify understandings and use of NHS 24 amongst Black and Minority Ethnic communities (REACH Community Health Project 2012), Gypsy/ Travellers, and people with learning disabilities, dementia and hearing impairments (all unpublished). While these projects did not necessarily have the same aims as mine, they were more appropriately targeted and resourced to enable the participation of these population groups.

3.2.2 Recruitment

The issue of how I would recruit participants was discussed at length as I was designing this research. The main priorities were to recruit the targeted group of callers, to minimise impact on NHS 24 service delivery and to ensure that I had access to no more personal data than necessary. A convenient approach would have been to identify suitable participants from call records and to contact them directly but this would have been ethically problematic as it would have required access to patient records. My preferred approach was to obtain prospective consent from callers before contacting them and the obvious way to do that was for NHS 24 nurses and pharmacists to ask callers at the end of a call for consent to be contacted with further information about the study. There was precedent for this in studies with callers to NHS Direct (O’Cathain et al. 2005; Rubin et al. 2010) and discussions with

NHS 24 managers suggested that it would be feasible, especially due to the relatively low numbers involved.

I produced an information sheet with recruitment instructions for staff, which briefly explained the background to the study and described which callers should be asked for consent to be contacted (appendix 6). I provided a brief script for staff to follow and made it clear that they were not expected to enter into any discussions about the research or answer any questions; if callers wanted to know more they would be sent an information leaflet. I also made it clear (I thought) that it was the *caller* I wished to speak to and not the patient in the case of third party calls. If a caller was willing to be contacted, the staff member was asked to write their name and address on a form which I provided and return it to me at the end of their shift. Because I wanted to interview callers soon after their call, I aimed to recruit participants in small batches over the course of the data collection period rather than all at once at the beginning. I started by asking nurses and pharmacists in one call centre only to assist with recruitment. As call centres receive calls routed from all over Scotland, this did not pose any risk of bias in terms of geographical location. Once potential respondents were identified they were sent an information leaflet about the research and a consent form to be returned if they were willing to take part in an interview.

During the recruitment phase, I would go to NHS 24 at the beginning of a shift and speak to each nurse and pharmacist as they arrived, explaining the study and what I was asking them to do and giving them an information sheet and a record sheet. I had hoped to only do this at the beginning, thinking that once staff were familiar with the process it would happen without me being present, but it became clear early on that if I was not present as a visible reminder the research was easily and understandably forgotten. After 2 months I had asked staff to recruit on 5 evening shifts, 1 night shift and over the course of 1 full weekend, but I had only received 62 names and addresses and completed 4 interviews. I realised that recruitment was going to take longer than anticipated. I submitted a substantial amendment to the NHS Research Ethics Committee asking for permission to also collect the telephone numbers of callers so that I could follow up my letters with a phone call. I hoped that this would encourage people to participate, or at least help me to understand their reasons for

not participating. This amendment was approved and I changed the instructions for staff accordingly. I also extended recruitment to a second call centre and made renewed efforts to engage staff and management in my research by sending around email updates and speaking to people face-to-face.

When I began to call prospective participants to follow up on the letter I had sent them, I found that most said they were just not interested in taking part in the research. Some hadn't received my letter and some had received it but hadn't read it. In some cases the NHS 24 staff member had written down the address that the call was made from, rather than the caller's home address. A small number of people seemed to be prompted by my call and said that they would return the consent form and others told me that they had already returned it, though I hadn't received it. I had some interesting conversations about why people didn't want to take part, for example one woman who lived on a rural farm said that she rarely calls NHS 24 and so wouldn't be a typical user. Despite my assurances that this made her just the sort of person I would like to speak to, she refused. She wasn't the only person who said that the problem they called with had been very minor and as it was now resolved there was no point in an interview. Even those who did agree to participate sometimes seemed surprised that I was interested in talking to them about episodes to which they themselves attached little significance. This highlighted the challenge of overcoming people's own perceptions of my research and, in particular, the difficulties of researching trivial or mundane illness episodes which, to potential participants, do not seem worthy of discussion (see also Cunningham-Burley 1990).

When I was in the call centres I spoke to staff about what they were being asked to do and how they felt about it. Many told me that they 'always forgot to ask' and some said that they had asked people but consent had been refused. More than one nurse explained that it was uncomfortable for them to ask callers about the research, especially as they thought that people often want to be seen and are unhappy about being given self-care advice. Similar issues have been reported in other studies which used gatekeepers to recruit via telephone (Hanlon et al. 2003; Niemann et al. 2004; Kimport 2012). It was therefore quite clear that there would be some, possibly considerable, selection bias as a result of recruiting participants this way. A small

number of nurses said that they were interested in research and were particularly keen to help. These few nurses between them accounted for most of the participants that were eventually recruited and their engagement was invaluable.

I also realised in speaking to the staff that there was some confusion about what was meant by a 'self-care' outcome, as nurses seemed to be interpreting it differently. Some told me that they give self-care advice but also tell people to make a routine appointment with their GP and they weren't sure whether or not this should be included. At first, I explained that I wanted them to include only people who were given a final disposition of 'self-care', regardless of what else they had been told. One nurse said she thought it was interesting that she often feels like she gives a lot of self-care advice but had realised that what she is doing is advising people to see their GP the next day and just giving interim self-care advice. Another nurse told me that he rarely gives 'pure self-care', but almost always tells people to contact their GP, both in order to legitimise their concerns and because he considers that GPs are the gateway to services. He said that although these people would meet my criteria, he gives them a different outcome. These conversations made me rethink my instructions to staff and after 4 months and 12 interviews I changed them to include all self-care advice, 'non-referred' and routine GP outcomes.

Over a period of about 6 months I sent out approximately 300 letters and received 38 replies. Of these, 30 people then agreed to take part in an interview.

3.2.3 The participants

Using gatekeepers to assist with recruitment of participants has many benefits but also, as noted above, some disadvantages. One of these is that NHS 24 staff did not always follow the recruitment instructions accurately. Apart from the confusion about what was actually meant by 'self-care advice' as I have discussed, 2 of the eventual participants were people who had been referred to a Primary Care Emergency Centre and one had been sent to A&E. Because I did not have access to information about the calls, this did not become apparent until during the interviews. In addition, in spite of the instruction to collect the name and address of the person who had *made* the call, in 5 cases the interviewee was the patient but not the caller. I

have decided to include all of these accounts in my analysis as they are not significantly different enough to warrant being excluded and in some cases provide a useful contrast. I have drawn attention to the differences where necessary.

In 9 cases, a second person was present for all or part of the interview. In 7 cases this was the interviewee's spouse and in 2 cases the interviewee's adult son or daughter. In some interviews this second person contributed significantly to the interview, and where this happened I asked them to complete a consent form so that I could include their accounts. As a result, 7 of the interviews are noted as being with 2 people. The table below presents the participants and includes their pseudonym, age, whether they live in a rural or urban area (according to Scottish Government classification by postcode) and their reason for calling NHS 24 as they described it in their interview. This information is provided in order to show the range of participant demographics and call reasons and to give context to the accounts presented in the analysis.

Pseudonym	Age	Who the call was about	Urban/rural	Call reason given in interview
Peter (wife Anna also contributed)	34	Called for child	Urban	Earache- 3YO child, no other symptoms
John	53	Called for self	Urban	Nosebleed, warfarin user, multiple morbidities (sent to PCEC)
Maggie	41	Called for self	Urban	Cut and swollen feet and ankles
Alison	56	Called for self	Urban	Dizziness, feeling faint, diabetic
Tina	53	Tina's husband called on her behalf	Rural	Medication error, feeling panicked, mental health problems
James	46	Called for self	Urban	Severe back pain, history of back pain

Claire	34	Called for child	Rural	Temperature- 2.5YO child, had been seen previous day suspected penicillin allergy
Josie	65	Josie's daughter called on her behalf	Urban	Mouth swelling, blistery rash, had been seen by GP suspected allergy (sent to A&E)
Laura	36	Called for child	Urban	Spots- baby 1 week old, looked like chicken pox
Angela	36	Called for child	Urban	Earache- 9YO child, no other symptoms
Paula	56	Called for self and husband	Urban	Both had diarrhoea, 1 vomiting, severe stomach pain
Robert	62	Called for self	Rural	Stomach pain, nausea, history of stomach ulcer
Debbie (husband Euan also contributed)	35	Euan made the call for Debbie	Urban	Open sore on leg, dressed by nurse, looked raw when dressing removed
Matthew (wife Ingrid also contributed)	75	Matthew made the call for Ingrid	Rural	Pain in upper leg/hip, couldn't walk, no other symptoms
Doreen	61	Doreen's husband called on her behalf	Urban	Pain/bruise/swelling on hand, site of earlier canula insertion
Nancy (son Michael also contributed)	71	Called for self	Urban	Diarrhoea, diabetic and taking Metformin- leaflet said to call NHS 24
Katie	23	Called for child	Urban	Crying baby- 6 months, temperature, straining, couldn't be calmed
Irene	58	Irene's partner called on her behalf	Urban	Diarrhoea & vomiting, partner recently hospitalised with Norovirus
Heather	31	Called for child	Rural	Swollen groin- baby 8 months, rash

Tracey	22	Called for self	Urban	Tonsillitis, vomiting, couldn't swallow antibiotics or own saliva
Jim	62	Called for self	Urban	Back pain, on medication for diabetes and heart, not sure what painkillers to use
Lauren	21	Called for self	Urban	Lump on side of abdomen for a few weeks, developed severe pain, short of breath (sent to PCEC)
Steven (wife Julie also contributed)	41	Called for child	Rural	Hand, foot and mouth- 2.5YO, not eating or drinking
Grace	36	Called for self	Urban	Earache, severe pain
Andrea	40	Called for self	Urban	Stomach pain, dizzy, history of stomach problems and hiatus hernia
Andy	24	Called for self	Urban	Diarrhoea & vomiting, 5 days
Tomasz (wife Irena also contributed)	34	Called for child	Rural	Temperature- 1YO baby, lethargic
Grant (wife Jodie also contributed)	33	Called for child	Urban	Mouth injury- baby 11 months, slipped in bath, bleeding
Gail	34	Called for self	Urban	Concussion, sleepy and nauseous, not vomiting
Natalie	28	Called for self	Urban	Nosebleed, headache, just started contraceptive pill

Table 3: Overview of interviewees

3.3 Interviewing

I aimed to interview people as soon as possible after their call to NHS 24, preferably within one month, to increase the likelihood that they would recall the events surrounding their call. This was generally feasible though it proved difficult in some

cases, particularly where long-distance travel was required. Each interview took place in a location convenient for the interviewee, this was most usually their home but 2 interviews took place in the participant's workplace and 2 in a café. Interviews took about an hour on average; the shortest was 17 minutes and the longest was 1 hour 40 minutes.

I began with 'situational rather than abstract' questions (Mason 2002: 64), asking interviewees to tell me about the specific contact with NHS 24 during which they had been asked to take part in the research. I explored the circumstances leading up to the call, what was discussed during the call and what happened afterwards. I asked about what people had done in terms of self-care or lay consultation before the call, probing on use of the internet, books or leaflets and speaking to friends and family. I then introduced more abstract questions such as how they had felt about the outcome of the call and why they decided to call NHS 24 rather than taking an alternative course of action such as self-care, going to A&E or waiting for a GP appointment.

I aimed to situate that particular decision to call NHS 24 in the context of the interviewee's illness behaviour and use of health services more generally and so I asked about their general health and past experiences of using health services. I explored what participants considered to be the major influences on how they deal with health concerns, probing for example about how they remembered parents dealing with illness and if they thought this influenced their own behaviours as adults. I also asked about awareness of media campaigns designed to encourage appropriate use of health services. I explored whether or not interviewees thought that their experience of using NHS 24 might influence how they would react in a similar situation in the future. I finished each interview by giving the participant the opportunity to add anything they wanted to tell me that I hadn't asked about and also to ask me any questions.

3.4 Analysis and writing

Analysis was not a clear-cut phase in this research project but something that I did throughout the entire process. I analysed the conversations I had with people during my observational fieldwork, making detailed notes and highlighting ideas that were

of interest. I then did a thematic analysis of these field notes which informed the design of the focus groups. I analysed the transcripts of the focus groups thematically and the findings informed the development of my interview questions. My analysis of the interviews happened even as I was carrying them out; the direction of questioning in each one was informed by the interviewee's account and my field notes from the interviews record emerging themes and ideas. Analysis continued as I wrote about the data, particularly as I began to describe the connections, contradictions and meanings that I could see in the accounts. This section describes in more detail the process of transcribing, coding and systematically analysing the interview data and writing up the findings in this thesis.

3.4.1 Transcription

The interviews were all audio-recorded and then transcribed verbatim. I transcribed most of the interviews myself but 6 of the interviews were outsourced to a transcriptionist to save time. This was done in accordance with Centre for Population Health Sciences policy and an approved service provider was used. I checked each of the outsourced transcripts and corrected them wherever necessary so that the final transcripts all had the same style and format. Transcription itself formed part of the process of analysis because it highlighted the importance of the ways that people say things, where they choose to place emphasis and the words they choose to use. I decided to transcribe verbatim in order to attempt to capture these meanings and so my transcripts include mispronounced words, Scots words, pauses, laughter and many idiomatic turns of phrase. My use of punctuation in the transcribed quotes reflects the rhythms of the original speech rather than grammatically correct sentences. However, it is questionable how accurately a researcher can ever reproduce spoken words in written text (Ross 2010). The transcribed accounts are, and can only be, the result of choices I have made about how to interpret what was said. It is important to acknowledge that transcription is not neutral and that theoretical considerations inform the way in which the interview comes to be represented as text (Lapadat and Lindsay 1999). For example, it has been suggested that using people's own vernacular rather than standardised academic language could lead readers to make assumptions about the background and status of participants

and that the transcription may not reflect how the interviewees would have chosen to represent their own words (Oliver et al. 2005). However, I agree with Davidson (2001: 180) that attempting to ‘smooth out’ difference doesn’t do anything to challenge prejudice and may in fact distort participants’ own meanings. With all of this in mind, I have tried to transcribe in a way that I feel is faithful enough to participants’ speech to convey their meanings as I have understood them and also in a way that I hope is respectful of the participants.

3.4.2 Coding and analysis

I coded the interview transcripts with the assistance of NVivo data analysis software (QSR International). I used thematic analysis (Braun and Clarke 2006) which involves immersion in the data, repeatedly reading and interpreting accounts and searching for ‘patterns of meaning’. I developed a mixture of a priori codes such as ‘reason for call’ and inductive codes such as ‘responsibility’ and ‘importance of clinical knowledge’. I coded the first 8 interviews soon after completing them and identified themes which helped to inform some of my questioning in the remaining interviews. For example, I realised after analysing a small number of interviews that people were talking about being worried that their symptoms, although minor, may have been an indication of more serious illness. I coded this as ‘risk’ and in later interviews I asked people for more detail about what they were worried about when they decided to call NHS 24. I later recoded the first 8 interviews along with all of the others. Initially, I coded very broadly, identifying as many themes as I could until I wasn’t creating any new codes. I then put all of the codes into a ‘mind-map’ format in order to identify connections and over-arching themes. Once I had identified the broad themes of most theoretical interest, I went back and recoded these into more detailed and specific sub-codes.

In my analysis, I sought to identify *how* people talked about the issues raised in the interviews, for example the kinds of discourses they drew on, and where opinions seemed to be based on stereotypes as opposed to personal experiences. I also sought to identify the issues that seemed of most importance to the interviewees themselves. My analysis revealed anxieties about symptoms, worries about risk, a need for

reassurance, a lack of confidence in peoples' own ability to assess symptoms and a need for 'professional' advice. These became the issues around which the thesis would be structured. I attempted to identify the common ideas that were shared by many participants, but also to give some indication of the diversity of opinion that exists (Krueger 1998). Inevitably, as with any qualitative analysis, the interpretation I offer is only one of many possible interpretations of the data and it reflects the epistemological assumptions underpinning my research design (Mason 2002), the conceptual and theoretical foundations outlined in chapter 2, and the personal values I bring to the research, which I reflect on further in section 3.5.

3.4.3 Writing

As with transcription and coding, the process of writing is not a neutral one and it involved further choices, specifically about what to write and how to write it. I have necessarily chosen how to interpret the voices and views of the interviewees and I have selected what to present as evidence (Mauthner and Doucet 2003). By including particular quotes and excluding others, I inevitably show each interviewee in a particular light which may not be how they would have chosen to present themselves. I have tried to be alert to this and to think about each quote in the context of the whole interview in order to avoid, where possible, attributing views to someone that they may not actually hold. I found it helpful to keep brief notes about each interviewee pinned to a wall above my desk and to have the research journal containing my field notes next to me as I was writing. This allowed me to constantly remind myself who the interviewee is and the context of their interview as I used extracts from their interviews to illustrate particular themes and areas of analysis.

I have tried to contextualise the quotes I use, explaining where a comment is typical of many interviewees or where it is markedly different. Sometimes I chose quotes because an interviewee phrased something in a particularly interesting or clear way. Sometimes I have used quotes to show how people can contradict themselves or hold more than one viewpoint simultaneously. In each case I have tried to be clear about why I have used the quotes that I have chosen. Finally, I have chosen to overtly put

myself into this research by using the first person throughout. However, I have aimed to represent a range of viewpoints without privileging my own (Mason 2002).

3.5 Reflections

I kept a research journal throughout this project in order to record my thoughts and ideas, the choices I was making and what I was thinking and experiencing as I carried out the research (Mills 1959). I have drawn on the notes I made in this journal while carrying out my analysis, while writing about the research and while reflecting on what I have learned and experienced.

Reflexivity has been important throughout this process in a number of forms. I have reflected on how my own experiences might affect how I understand the experiences of others and I have also reflected on how relations are structured in the research setting, affecting the way that accounts are generated (Finlay 2003). I have tried to remain actively aware, throughout the research process, of my own attitudes and values, my social position and my unconscious motivations or biases (Finlay 2003). In this section, I discuss in more detail how I have been reflexive about the process of research, myself as a researcher and the nature of the accounts generated in this research.

3.5.1 On the process of research

The process of carrying out this research involved some challenges, particularly at the recruitment stage as described in section 3.2.2 above. Negotiating access to participants was more difficult than expected, although it would have been much more difficult had NHS 24 not been sponsoring the project. Once I started to recruit interviewees, realising that my plan wasn't working led to feelings of frustration and disappointment and required me to make decisions about altering my methods after ethical approval had been granted and recruitment had begun (McCormack et al. 2013). This aspect of the research process in particular generated a lot of reflection about the choices I had made and how I might have done things differently.

I also found the process of carrying out the interviews challenging in some ways. Participants in this study live all over Scotland and in order to interview them I

travelled sometimes quite long distances, mostly using public transport. This meant that interviewing was often physically as well as mentally demanding. Most of the interviews took place in participants' homes which were all very different; sometimes in affluent areas and sometimes in areas which were extremely deprived. Travelling to people's homes, while sometimes challenging, was a privilege and it gave me a sense of the differences between the participants and the very different social and geographical contexts in which they live their lives. This insight was invaluable when it came to understanding their accounts.

I also reflected on the different ways in which the interviewees seemed to view me; for example, in spite of having specified in the participant information leaflet that I am not a healthcare worker, I got the impression in a small number of interviews that I was viewed as such and had to take steps to clarify that I am not. I also got the impression that some participants didn't fully understand the purpose of the research, or that they hadn't explained it to family members who were also present. Doreen's husband, for example, was overtly suspicious of me at first and wanted to know why I was asking Doreen 'personal questions'. Often people's lack of understanding only became apparent during the interview, even when I had explained the purpose of the research and the interviewee told me that they had read and understood the information leaflet. This emphasised to me the difference between procedural ethics and doing ethical research; it was not enough to assume that because people said they had no questions that they had really understood.

This was a particular concern in the interview with Alison which took place early on in the study and lasted only 17 minutes. In many ways, this interview felt like a failure. Alison had a very poor memory and couldn't recall much about her call to NHS 24. It seemed strange therefore that she had agreed to take part in the interview and it was only afterwards that I wondered if she had seen an official-looking letter which mentioned NHS 24 and replied to it because she thought she had to. I did suspect before the interview that Alison may not have been fully aware of what the research involved and I was careful to spend time explaining and obtaining consent. She seemed to be fully capable of consent and her teenage daughter was present throughout the interview so I went ahead with it on that basis. However, Alison gave

a lot of one-word answers to my questions or replied that she ‘didn’t know’, as a result of which I had to prompt quite extensively and I worried that in my keenness both to reassure her and to elicit answers I may have been leading her too much. Nevertheless, Alison’s contributions were valuable and there was much to learn from what little she said as well as what she didn’t say. I benefitted from reflecting on what I could learn from this ‘failed interview’ (Nairn et al. 2005) rather than dismissing it completely.

3.5.2 On the self

As noted already in this chapter, who I am as a person and as a researcher, the various ‘selves’ that I bring to my research and the ‘situationally created self’ that emerged in the context of the research (Reinharz 1997) have all impacted on my research design, data collection, analysis and findings. It is important to recognise the significance of autobiographical details (Munro et al. 2004) in reflecting on these selves and in being transparent about how they have variously emerged or been hidden throughout the research. A researcher’s structural and personal biography influences their relationship to their object of study (Gray 2008) and it is necessary to ‘reflect on and dissect the personal and political *motivations* that matter in how we come to our research topics’ (Doucet 2008: 75 original emphasis).

My own structural and personal biography is intertwined in many ways with the subjects of my research; health services and health service users. I have not used NHS 24 myself and so had no pre-existing personal views on the service. However, I have an academic background in health related social sciences and I have previously worked in health services and health care settings. My parents are a doctor and a nurse and I have been exposed all my life to their ideas about the realities and the politics of health services. My parents are both strongly committed to advocacy for patients and a desire to improve things where they see a need and this has certainly permeated into my own values. I agree with Becker (1967: 239) that it is impossible to do research ‘uncontaminated by personal and political sympathies’ and that when we ‘take sides’ it is important to acknowledge whose side we are on. I am reflexively aware of my own tendency towards advocacy of patient perspectives. This has also

been influenced by my experiences of being a patient, one example of which was particularly salient during this research.

Between the pilot study and the interviews, I underwent a tonsillectomy which took several weeks to recover from. At the time, I wrote in my research journal about my personal experience of illness and reflected on my ‘patient self’. In particular, I noted feeling reliant on others during my recuperation, feeling vulnerable and needing support and reassurance. I was in daily phone contact with my mother (who lives in Ireland) which made me think about the importance of family support, even from a distance. I was taking a variety of strong medications which caused me to feel confused and nauseous. I wanted to take something to relieve the nausea and had suitable medication in my first-aid kit which in other circumstances I would have self-prescribed. However, pain and exhaustion made me less confident and decisive than usual, so I phoned the ward on which I had been a patient to ask a nurse for advice. As my throat began to heal, I worried about the scarring and went online to look up information about ‘normal’ healing. I initially searched medical literature but actually found reports of patient experiences on web forums more useful and reassuring. When I came to think about the interviewees’ accounts, I realised how much reflecting on this experience helped me to understand other people’s illness behaviour in a way that I might not have otherwise.

3.5.3 On the ‘truth’

Representation of a ‘standard’ or ‘average’ account was never the aim of this study. Each of the participants brought a unique perspective which may not be empirically generalisable but which is nonetheless of theoretical interest. It is important to note that these accounts have been co-constructed in this specific research context; had the research been carried out by another researcher, or in another time or place, the data generated may have been quite different.

I use the term ‘account’ throughout this thesis to refer to the stories shared by participants in the interviews. Accounts can be understood as the explanations that people weave to suit particular circumstances or to answer particular questions; they incorporate ‘aspects of meaning, of moral evaluation, and of broader ideology or

worldview' (Stainton-Rogers 1991: 2). In interviews about health and illness, accounts are produced in a context where people may perceive questioning as potential criticism and may feel a need to justify themselves (Radley and Billig 1996). People may rationalise their illness behaviour after-the-fact and use the stories they tell about particular illness episodes as a way of making sense of them (Cunningham-Burley 1990). It is also important to pay attention to the culturally available discourses that are likely to shape people's accounts, for example those found in the media and in political rhetoric, as 'the notion of discourse sees language and imagery as having a constitutive role in producing social relations and notions of reality' (Lupton 1998: 195). In talking about health and illness, people draw on 'the language, beliefs, ideologies, metaphors and representations that are available to them' and therefore their accounts are likely to reveal 'as much about the culturally available discourses as it does about the minutiae of the teller's life' (Nettleton 2013: 74).

There is a possibility that participants were sometimes telling me what they thought I wanted to hear or were conforming to conventional accounts in order to construct themselves in certain ways. Some participants were much more reflexive than others, and all used the interviews in different ways to create the accounts, and the 'selves', that they wanted to present. Cornwell (1984) distinguishes between 'public' accounts which tend to conform to social expectations, usually given in direct response to a question or to someone with whom the respondent has not built up a rapport, and 'private' accounts which emerge in more unguarded conversation or via circuitous routes and reveal a more personal picture. However, the distinction between public and private accounts is not always clear, and aspects of both types may co-occur in the stories people tell (Radley and Billig 1996). In my interviews, public accounts almost certainly dominate, but some private accounts were also revealed. Rather than seeing this as a limitation of the study, I have used it as a foundation of my analysis and throughout this thesis I have engaged with the ways that interviewees chose to present themselves and to construct their accounts.

It is impossible to know if what was recounted by the interviewees is what 'really' happened when they called NHS 24. Some people contradicted themselves or

admitted to not having a clear recollection of details. In some of the interviews where 2 people were present they remembered events differently. For example, Tomasz and Irena had very different recollections of their baby's illness. Tomasz told me that the baby had a temperature but no other symptoms and that they had taken no further action after calling NHS 24. Irena recalled the baby being lethargic and behaving strangely; she said that she brought him to the GP the next morning where he was diagnosed with tonsillitis. Previous research has shown that patients tend to have good recollection of the most salient content of GP consultations, both face-to-face and over the telephone (McKinstry et al. 2011). However, in Niemann et al.'s (2004) study of calls to a Swiss medical call centre, only 78 per cent of patients recalled the same triage decision as had been actually made when followed up one week after their call. I have conducted this research from the position that there may be 'multiple realities' none of which is necessarily the 'truth' (Barbour 2008: 28), and it is with this caveat that I go on to present my findings in the following chapters.

4. Understanding NHS 24

In chapter 2, I established that the way health services are organised influences the way that people use them and that availability of and access to services is one determinant of help-seeking behaviour. I also introduced the idea that the proliferation of routes into care in the Scottish health system means that people must engage in a process of assessing and categorising their symptoms in order to determine the most appropriate service from which to seek help or advice. In this chapter, I present data from the pilot study focus groups and from individual interviews which show that both staff and service users have broad and varied understandings of the role and purpose of NHS 24 and how it operates. I argue that these diverse understandings lead to people using the service in different ways, and that the blurred identity of the service allows people to use it in ways which meet their particular needs at a particular time. This also allows for flexibility in the way that both staff and callers co-construct legitimacy and definitions of appropriate use (Hillman 2014). However, lack of clarity around role and purpose also means that people may have unrealistic expectations of what NHS 24 can provide, and this may lead to dissatisfaction (Wilson et al. 2001; McKinley et al. 2002). A lack of certainty about what NHS 24 is for also led some participants in this study to express anxiety about their service use and whether or not it was appropriate.

4.1 Understandings of how NHS 24 works

My interest in how people understand NHS 24, and particularly the unscheduled care service, began during my observational fieldwork when I became aware of the broad range of reasons why people call the service. It was clear that staff, callers and partner organisations had very different ideas about what NHS 24 is for, and differing expectations of what the service could and should provide. The staff I spoke to during observations attributed this to a lack of public education about health services in general and a lack of awareness amongst both the public and other professionals about appropriate routes for accessing health care or advice. This view that there is a need for more education about how to use health services was echoed by many participants in my focus groups and interviews. This section outlines the

range of understandings that were expressed by participants about how NHS 24 fits with the rest of the health system, how it is staffed and whether it is a 24-hour or out-of-hours service.

4.1.1 NHS 24 and the health system in Scotland

In the focus groups with staff and members of the NHS 24 Patient Participation Forum and Clinical Governance Public Panel, there was a lot of discussion about the need for people to be educated about how the whole health system works and how to access services. The focus groups with lay people and the individual interviews confirmed that people don't always have a clear understanding of the health system, and in particular how the different services fit together. People quite frequently referred to 'the NHS' as if it is a single entity, encompassing NHS 24, hospitals and primary care services. Although integration may be a policy aspiration (Scottish Executive 2000; 2005a), it is still the case that services operate quite independently. This can be confusing for people, as the different parts of the NHS do not always connect up as well as we might expect. For example, NHS 24 does not have access to patient records from GPs or hospitals, only to records of previous contacts with NHS 24 and an Emergency Care Summary with basic details such as medications and allergies, although NHS 24 does share call records with GP practices.

The callers I interviewed were generally quite clear about the distinction between NHS 24 and their GPs. They saw them as very separate services, although most people thought that they *should* be more joined up. Some interviewees assumed that NHS 24 staff have access to more information than they actually do and most of them told me that they think all services should have full access to information held in health records. In fact only one interviewee thought that information shouldn't be shared, as part of the appeal of NHS 24 for her was the anonymity it afforded. Callers were not necessarily aware that NHS 24 call records are shared with GPs, particularly in cases where calls hadn't been followed up.

Heather: *Yeah, I think everything, his whole medical history, no matter where it's recorded should be, you know, put in the one place. Ehm, yeah definitely, uhuh. I definitely think that, yeah. Because I mean if it happened*

again, I would like the doctor to already know, or, I don't know if a follow-up was really necessary in this case... but... I don't know.

Katie, who called about a young baby, similarly saw value in sharing records as it would allow the GP to recognise patterns or an on-going problem, a benefit also mentioned by a number of other interviewees.

Where confusion more often arose for interviewees was in making a distinction between NHS 24 and the out-of-hours services run by local health boards. Sometimes, when people are referred to an out-of-hours GP by NHS 24, they assume that these doctors are employed by NHS 24, as illustrated by references to '*NHS 24 doctors*'. Others seem to think that their local Primary Care Emergency Centre (PCEC) is part of NHS 24, so that people talked about '*going to NHS 24*'. Staff identified this as a potential source of frustration both for themselves and for callers, because it can lead to unrealistic expectations of the help and support they can provide, and the level of influence they have over the care that patients go on to receive from other providers.

Mary [nurse-staff FG1]: *I think that there is some people that don't have a good understanding of what we do. I think they, they overestimate what our remit is, and what powers we do have, you know. Like, even just, when we say, you know, you need- can you go and see your GP? 'Well, can you no make me an appointment?' You know, 'No. We don't have any access.' And even though you ask, you're doin' the set questions with the Emergency Care Summary, people think that's their notes, people think we're actually sittin' lookin' at- 'Oh you'll be able to see fae ma notes'. 'No, no that's not what we get access to'. You know, I think people see us interlinked at times.*

Sandra [nurse]: *It's difficult, aye, when they're on, when we're on the other end of a phone in a call centre, you know and your patient's up in Lerwick and, you know, they're goin' 'And where are you hen?'*

Mary: *They think we're there. And they say 'So can I come up and see you?' 'Well you can try!'*

Stephanie [pharmacist]: *I'd be very interested to see how, what percentage of the population know that the out-of-hours service is a different service from us.*

A number of interviewees expressed some uncertainty about how out-of-hours care is arranged in their own localities. Some were confused about whether or not it is still possible to get a home visit from a GP out-of-hours, and others were confused about

when the switch from GP cooperatives to NHS 24 had happened, or if it had even happened at all.

Euan: *NHS 24, 999, I mean there's other things as well, you've got 24-hour [GP cooperative], well we used to have the doctor you could phone 24 hours and that but I mean that's stopped now as well I think, I think it's just NHS 24 innit? So, I think that's, is there any other ones you ken? What else is there?*

Debbie: *Ehm, naw I think [GP cooperative] is finished. That was the emergency service in [nearby town].*

Euan: *They were good as well; I'll tell you they were good.*

Debbie: *That was for, oot ae hours doctors.*

ED: *Right*

Euan: *They were fantastic.*

Debbie: *Aye. But that's stopped as well I think; they said it's the NHS 24.*

Euan: *Aye, it's NHS 24's number.*

Robert, who was unhappy with the advice he received from NHS 24, was under the impression that his local surgery was still available out-of-hours, although he wasn't entirely sure.

Robert: *I think they maybe do a good job in cities where GPs are not contactable out-of-hours, a lot of, I don't think our own, ehm, ah I think if we phone the surgery here we get an emergency number to phone if required, you know out-of-hours. Ehm, so we've no real need for NHS 24.*

ED: *I didn't realise- so your surgery is still providing out-of-hours themselves?*

Robert: *I'm sure, I'm sure, there's an emergency number you can contact, ehm and there'll be a doctor on duty obviously, you know out-of-hours, for call-outs when it's required. But I suspect they try and keep you to normal workin' hours if they can, but I'm near enough sure there's an emergency number.*

Having questioned him about this, I later looked up Robert's surgery and in fact it automatically reroutes calls to NHS 24 when it is closed. This is something which may add to confusion for some people if they don't understand that their call has been rerouted.

A further issue is people's limited understanding of the difference between NHS 24 and NHS Direct. This is something I come across quite regularly when talking to people about my research and it seems that perceptions of NHS 24 may have been tainted to some extent by the problems experienced by NHS Direct in England before it was closed. In the focus group with women over 65, Anne referred to '*NHS Direct*' throughout the discussion, and Sally told a story about the poor service she received when contacting what she referred to as '*NHS 24 in Newcastle*'. When I asked her about this, her response showed that she didn't see a clear distinction:

ED: *When you say you were in Newcastle, were you phoning NHS 24 or NHS Direct?*

Sally: *It'd be NHS Direct.*

ED: *Right, ok, just for clarity.*

Sally: *Yep. It's a slightly different service but it's the same thing.*

It is worth noting that this research was carried out before NHS 24 changed its contact number to 111, a number which has already become associated with problems in England (Parkinson 2013; Guardian 2013). It is possible that this could make the distinction between the services even less clear to the public. This matters because, as a review of NHS 111 (NHS England 2014) points out, lack of distinction between the different services operating in the health care system can lead to one service being 'blamed' for the failures or faults of another, with repercussions for the reputation of the service that is blamed.

4.1.2 How NHS 24 is staffed

As well as some confusion about how NHS 24 operates and how it fits into the wider health system in Scotland, there can sometimes be confusion about how it is staffed and who a caller speaks to when they call. Most of my respondents had some general understanding of the process and many correctly assumed that calls are answered by a call handler and then transferred to a nurse or other clinical adviser, but often they were not entirely certain about this. Some people were unsure if call handlers have clinical training, and a small number of people were unsure if anyone they spoke to was clinically trained. For instance, Peter mentioned getting '*professional or semi-professional advice*' and also expressed uncertainty about who he actually spoke to:

Peter: *I think I spoke to somebody; they took down a few details, and then transferred me on to somebody else, ehm, so I don't know if it was a sorta call handler and then get transferred on to like a nurse or somebody with medical training background, ehm...*

Maggie similarly mentioned '*the adviser who phoned back later on, I don't know if she was a nurse or not*' and also expressed her uncertainty about the level of expertise of the person she spoke to:

Maggie: *I guess the thing with phoning the phone lines is you don't know if it's a trained medical professional or if it's just someone who's looking at the same thing you're looking at, I don't know if it's someone who answers calls, or if it's a nurse, ehm I think they do make that clear but I think in the back of your head you don't know.*

In the focus group with women over 65, Sally explained to Anne how NHS 24 is staffed. Anne didn't realise that calls are directed to a call centre, but rather thought that they were answered by a nurse or doctor. Sally is more aware of the process than many other respondents, but still her reference to the '*expert doctor*' or '*nurse in a particular thing*' shows that she thinks calls are streamed more specifically than is realistically the case. Her comments also suggest that she doesn't have an understanding of the way that calls are prioritised.

Sally [Over 65s FG]: *You get, you get somebody who's answering who takes the information and is actually screening what, what you're saying.[To ED] I mean obviously they will have some degree of, of training?*

ED: *They, they will just be screening out anything immediately, make sure it's not immediately life-threatening.*

Anne: *Mmmhmm.*

Sally: *And then it gets passed on. Now if, if you're fortunate, I assume, there might be somebody who is there available as they're passing the information on who can immediately come on to the phone. I've certainly never experienced that and I don't know anyone who has experienced that, they've had to wait to get a phone call back. Because presumably, the expert doctor in whatever, or nurse in a particular thing may well be answering a- another call. So I assume they are understaffed. Don't know if that's right but that's an assumption.*

Debbie and Euan seemed to be under the impression that the staff in NHS 24 are actually working in a clinical setting. Again this may be because they are thinking of

NHS 24 and the PCEC as the same service, and imagine that their call is being taken in the out-of-hours clinic.

Debbie: *Aye the bottom line is we think the NHS is good, and it is helpful, and it does save a lot ae folk fae goin' up and annoyin' the nurses in the hospital, and it saves waitin' times as well cos there, I woulda went up there and I woulda taken up a cubicle, I woulda taken up a nurse's time, a doctor's time, and somebody that really needed it, is sittin' waitin'. So there, they managed to deal wi me ower the phone, and that was it, done, sorted.*

Euan: *Aye but the good thing is, alright it's takin' them away from their job they're daein' in there but at least they're only daein' it for like 10 minutes and if they did need that sortae, I think if they needed a consultation wi maybe a surgeon or somebody that was there at the time they'd probably get that and say well 'Come up', you know what I mean?*

As well as references to seeing 'NHS 24 doctors' as mentioned previously, a number of people told me that when they called NHS 24 they spoke to a doctor or a doctor phoned them back. It is possible that in the past their calls may have been passed to a PCEC, as sometimes happens, or that they received a call from one of the very few GPs who work in NHS 24 at busy times, but it is highly unlikely that this happened on the occasion that I was interviewing them about as they would not have received information about my study unless their call was closed by a nurse or pharmacist. Matthew's understanding of the service is that there is a 3 stage process involving a call handler, a nurse and a doctor.

Matthew: *Yes, the only thing that I think, and this is a thing the other people were saying, you go through 3 stages. You speak to somebody who seems to be like a receptionist, who then transfers you to some, a nurse or someone with medical training, who then transfers you to the appropriate doctor.*

Sometimes people feel that they are being passed around from person to person, and being asked the same questions, with little differentiation (that they are aware of) between the staff groups. Matthew was certain that during his recent call he had spoken to 3 people, and I attempted to clarify why this might have been but I wasn't able to get a clear picture of what had happened during his call. He remained adamant that he spoke to a call handler, and then to 'someone else' before being told a nurse would call him back. Again, the fact that callers don't always understand who they are talking to when they call NHS 24 may not be very significant as long as

they receive clinically appropriate care and feel that their needs have been met. However, it may have an impact on their satisfaction with the service if they feel that they are being passed around without understanding why.

4.1.3 A 24-hour or out-of-hours service

As discussed in chapter 2, it is understandable that there may be some confusion about whether NHS 24 is an out-of-hours service or a 24-hour service. It was pointed out by one staff member I spoke to that the name ‘NHS 24’ clearly suggests that it is a 24-hour service and that this clashes with messages that its purpose is to provide access to out-of-hours care.

The majority of interviewees see it very much as an out-of-hours service and told me that they would never consider using it when their GP surgery was open; indeed, some didn’t know that that was even possible, or allowed. When I asked people what they would do during the day if they needed help or advice, most said that they would contact their GP directly, and many said that they would request a telephone consultation with a doctor or nurse from their surgery. Interestingly – given that one of NHS 24’s original aims was to offer health advice in cases which may not be serious enough for a GP contact – this suggests that some people see contacting their GP as a more appropriate source of advice even about minor symptoms.

ED: *Yeah, so you wouldn’t phone, like cos even though it’s 24 hours you don’t think you’d use it during the day?*

Tracey: *Mmm nah, I don’t think so. But I, I was sure my mum had said to me that you weren’t meant to anyway if your doctor’s was open, d’you know what I mean? I would probably phone the doctor’s first. Or even like, if it wasn’t an appointment, even, you know you can phone and like speak to a nurse, over the phone, rather than phone that line.*

Peter, on the other hand, saw NHS 24 as a 24-hour service and the best service to call when unsure whether or not a GP appointment was necessary. Although he called out-of-hours, he actually thought that his GP surgery was still open at the time of his call. His wife, Anna, expressed surprise at his decision as she said that she would always contact her surgery if it was open.

Anna: *That's interestin' though because I was always under the impression that NHS 24 was there but the service should, it was more of a out-of-hours service if you couldn't get initial contact with your own surgery. Like, cos if you phone the doctor's surgery after 5 o'clock and it's closed whatever, you get, ma surgery anyway you get the automated message sayin' contact NHS 24 on this number, but ehm, I- I mean that was my understandin' to be honest, and if it was durin' the day I would phone the surgery first and use NHS 24 out-of-hours. But, I'm obviously- d'you know I just didn't realise, that's my understandin' of it-*

Peter: *I think it's there 24/ 7 isn't it? 24, 7!*

Anna: *Yeah that's what I'm sayin, I-, I just thought of it more, personally more as an out-of-hours service.*

For the small number of other people who said they would call NHS 24 regardless of the time of day or week, there were a range of reasons. Natalie calls whenever she needs advice and she sees this as less resource intensive and therefore more appropriate than contacting a GP. While for Lauren, who is registered with a GP in one city but at university in another, calling NHS 24 is the only way to get an appointment with a doctor if she is not at home. Lauren also called NHS 24 for continuity of care; when I interviewed her she had called twice about the same problem and she explained that she would have called regardless of the time of day or week because NHS 24 had dealt with her symptoms the first time.

A very small number of people expressed a consumerist attitude to the service, and suggested that they would use it at any time because it is there 24/7. However, this cannot be taken at face value as those with the most consumerist attitudes, Robert and James, both said that they would still prefer to call their GP surgery if it was open. It seems that what they were articulating is a *right* to call NHS 24 whenever they want to, rather than a wish to do so.

ED: *Ok, and when your back goes, do you just call at any time? Does it matter to you if it's in-hours or out-of-hours?*

James: *No it doesnae matter no, because I, the way I see it is it's, had it been like daytime hours I woulda probably phoned ma doctor's.*

ED: *Would you?*

James: *Aye. Ehm, and because, well to me the name itsel' NHS 24 means it's a 24-hour service eh? Eh, well that's the way I perce- that's my perception anyway.*

The staff I spoke to during observation and in the focus groups were very conscious that NHS 24 could be understood as either a 24-hour or an out-of-hours service. They also noted that the service provided in-hours and out-of-hours is different, something they thought that callers may not be aware of.

Stephanie [pharmacist- staff FG1]: *I think it can be confusin' for patients though, because you're, you'll get an automated voice message that this is the emergency out-of-hours service, when we are coverin' the GP practice. But then we're 24/7, so durin' the day we don't mind givin' them advice-*

Mary [nurse]: *Yeah*

Jane [nurse]: *It comes back to-*

Stephanie: *-durin' the day, Monday to Friday, we've got all the time in the world for them-*

Sandra [nurse]: *That's right*

Stephanie: *-and yet, ehm, in the out-of-hours it's suddenly a diff-, well, in our eyes a completely different service, cos we can't cope with them all wantin' advice at those, those times.*

Stephanie's comments here show awareness that the inconsistency in service provision may result in confusion for callers. Her understanding of the reason for this inconsistency is that the service 'can't cope with them all' in the out-of-hours period, and so the framing of general advice calls as inappropriate in the out-of-hours period is a direct result of increased demand at those times putting pressure on the service. Whether or not calls for 'advice' are seen as appropriate also depends on whether the service is understood as an emergency service, a primary care service or a service providing general health advice and support. The following section demonstrates that there is little consensus about this amongst either staff or service users.

4.2 Understandings of the purpose of NHS 24

As well as varying understandings of how NHS 24 operates, both staff and lay respondents in this study expressed quite diverse, and frequently inconsistent, understandings of the role and purpose of the organisation. What is most noteworthy is the extent to which people's stated understanding of NHS 24's purpose is often contradicted by the way they themselves have used it. The data presented in this section also highlights again the difficulty of discussing concepts such as

‘emergency’ and ‘urgent’ in the absence of a shared understanding of what these terms mean.

4.2.1 An emergency service

A common response when I asked people what they thought NHS 24 is for was that it is an ‘emergency’ service. Around half of the interviewees described it this way, and yet closer analysis makes it clear that there is no common understanding of what an emergency is. Furthermore, some people who described NHS 24 as an emergency service admitted that the situation they called about might not have been an emergency. Debbie, for example, said that she would only call NHS 24 in ‘*a complete and utter emergency*’, yet her most recent call to NHS 24 was prompted by a sore on her leg. This was of course genuinely worrying and she needed some advice, but she said it wasn’t something that she thought would warrant an ambulance or a visit to an emergency department. Importantly though, what is not considered to be an emergency in retrospect might have felt like one at the time. For example, Nancy had diarrhoea which she thought was likely to have been caused by her diabetes medication and the patient information leaflet said that if she experienced this side-effect she should seek advice. This, along with her discomfort, clearly increased the sense of urgency that Nancy felt at the time.

Nancy: *Well, I wouldnae, I wouldnae pester them all the time. No, just in an emergency.*

ED: *So, the fact, when you had diarrhoea, was that an emergency for you, do you think?*

Nancy: *Aye, well, I was mainly just, eh, I didnae, I wasnae looking for anybody to come out and see me. I just wanted them to maybe give me a bit ae advice on whether to stop taking my tablets or no. That was aw.*

The juxtaposition here of Nancy’s claim that she would only call in an emergency and her explanation that she just wanted a bit of advice is interesting and shows the complexity of establishing herself as a responsible service user. She must at the same time show that her symptoms were urgent enough to justify a call to NHS 24, while presenting herself as undemanding; ‘*I wasnae looking for anybody to come out and see me*’. The fact that the urgency of an illness episode can only be established with certainty post-hoc (Roberts 1992) means that this is a situation many interviewees

found themselves in. For example, Tomasz also told me that he thinks of NHS 24 as a ‘*helpline for emergencies*’, and said that he would avoid calling for ‘*a bit of advice*’.

ED: *So did you see the baby having a temperature as an emergency?*

Tomasz: [pause] *Not at the moment. But at that time yes, that was eh, I thought you know it might be- cos you know he was, perfectly well at the evening and then, you know it was, he was really hot at that point. So. Lack of experience probably.*

ED: *Yeah, so is it just because it happened quite fast and-*

Tomasz: *Because it happened with a baby.*

Of course, as Tomasz points out here, whether or not a situation is considered to be an emergency also depends on who is unwell, and so even a seemingly minor symptom in a baby could indeed be an emergency. It also depends on who is doing the calling and their perspective on the situation. Grace’s husband had wanted to take her to A&E when she had severe earache, but she had persuaded him to call NHS 24 for her instead. Yet, on another occasion, when he himself was experiencing chest pains, he chose to call NHS 24.

In both of the focus groups with staff, some participants expressed quite strong views that NHS 24 *is* an emergency service, in spite of their awareness that many callers as well as others within the organisation don’t see it that way.

Annabel [nurse- staff FG2]: *And like any service it grows and develops, we almost create that monster because now we have opened this up 24 hours and, I think the parameters of this service has just grown and grown and grown, it’s no longer seen as the emergency service.*

Joanne [call handler]: *No*

Simon [nurse]: *No, it’s not*

Sara [nurse]: *No... Oh, well, for us within the service, providing the service, yeah, but not to the public-*

Annabel: *Oh absolutely, but not to our customers, as such.*

Sandra [nurse- staff FG1]: *But there’s a lot of people in this place think we- and this isn’t a nurse or a call handler, there’s people in the organisation that don’t see our service as an emergency service-*

Mary [nurse]: *Really?*

Sandra: *-they see it as a primary care service, so whether it's ehm, you know your GP on Monday mornin', or your GP on Saturday mornin', it's a service that we provide. Aye, I was shocked as well!*

Mary: *And yet we're, we're not; I mean surely, we're not!*

For these frontline staff, out-of-hours callers with non-urgent symptoms can present a challenge as they need to be persuaded that whatever they've called about is not an emergency. This primarily seems to be an issue if the caller is insisting on an appointment.

Sara [nurse- staff FG 2]: *I'm sorry, I, I do sympathise, but you know that-, and we explain another way to sort of, go about things, but we have to say it's not an emergency, and that can be really hard, especially if you've got somebody who's being quite pushy on the phone. And you have to kind of pull it back and say well, and just be blunt don't you, and you say, it's not an emergency-*

Joanne [call handler]: *This is an emergency service that we're providing but, as you say the public see it differently.*

Interestingly, given the above comments, some of the staff also expressed surprise that some people will call NHS 24 in situations that require an emergency response. Sara described actually asking one caller why he had phoned NHS 24 for symptoms which required an ambulance:

Sara [nurse- staff FG 2]: *I had one my last night shift, a guy who has had literally about 4 heart attacks, the last one was only about 2 weeks ago, all his previous records, I think that there was maybe 31 previous calls, and out of the 31 of them about 28 of them were treble 9 ambulances, extensive cardiac history, and what was he phoning for? Cardiac sounding chest pain. Left sided chest pain, radiation to jaw and arm, feelin' nauseated, sweaty, clammy. I mean even if he didn't have a cardiac history that would be a di- a straight 9- and I said, and I actually had to say to him, 'Can I ask why?' I mean I'd arranged the ambulance and it was on its way but I went back to him and I said to him, 'Why, why did you ring NHS 24? You have these symptoms time and time again'. I said to him 'What happens when you ring us?' He goes 'Aw, youse just phone an ambulance'. I said 'Exactly, so why don't you then phone an ambulance yourself?'*

Sara couldn't remember what the man's response had been in this case, though some of the staff suggested that people can be in denial about the seriousness of their symptoms and they also acknowledged that lay people might have difficulty

assessing the severity of symptoms. They recognised that people can be reluctant to call an ambulance in case they are criticised for wasting the time of the emergency services, and Sara recalled another situation in which someone had told her that they didn't realise they *could* call an ambulance for themselves.

A very similar discussion took place in the other staff focus group when Mary, a nurse, recalled a time when she herself had called NHS 24 in a situation that she knew required an ambulance. Her experience highlights how difficult it is for people to make 'appropriate' decisions in stressful situations, even with clinical expertise.

Mary [nurse- staff FG 1]: *But then Sandra I've been in that situation, ma mum, you know. God knows what I phoned- cos the minute I spoke to a nurse I thought what am I doin'?*

Sandra [nurse]: *Aye, I suppose so, when you're panickin'.*

Mary: *You know, and I shoulda known better, but I thought, not-, but part, part ae me was thinkin' it's not that bad, it's not that bad, you know, it's not bad enough for an ambulance, just let me, just let me phone, you know. And it was, you know within seconds watchin' ma mum thought 'Oh jesus what am I doin'?' you know and, and, of course that lassie must have thought 'She shoulda known better!' You know, and, and phoned the ambulance, but it's easy done, because I was, in ma mind thinking- and it was only a really, really severe, severe vomitin' bug she had, but it came on so suddenly, and she was the cold, sweaty, clammy, she was very incoherent, and of course she started holdin' her chest, and I'm thinkin, 'Oh god' and I phoned here!*

Sandra: *I know cos you feel bad phonin' 999. Cos they're busy! [Laughs]*

Mary: *But it was only, I just thought 'Oh it's no that bad! It's no that bad, it's not as bad as I'm thinkin' it could be' but then the more, you know within seconds I thought-*

Sandra: *When you think about the answers to the algorithms, if you were doin' it sensibly, aye.*

Mary: *Yeah, I thought, 'What am I doin'?' I must look a right diddy', you know.*

Sandra: *No but I suppose you panic eh? And you do need advice.*

Mary: *You do panic. So I, I kind of, sometimes like that you do think 'They're phonin' here? You've wasted 10 minutes now gettin' to the point and you knew?' But I've done it, I've been there and it is, it's so easy done, because you're, you're panickin' and you just think it's not that bad, it can't be that bad, it can't be.*

Of course, not everyone sees NHS 24 as an emergency service. Some interviewees were quite clear that there is a distinction between urgent and emergency and said that they would only call NHS 24 if the situation *wasn't* an emergency. For example Heather and Claire, who both have young children, said that they would go straight to hospital in an emergency. Euan and Debbie, in spite of saying that NHS 24 was for emergencies, also said that they would take their children straight to hospital in an emergency.

This range of viewpoints shows that in the context of calling NHS 24, as in other contexts, 'emergency' is a contingent and situationally defined category. Both callers and staff find it difficult to manage the boundary between emergency and non-emergency and it is not clear what understanding NHS 24 as an 'emergency service' actually means in practice.

4.2.2 'Like a doctor'

In contrast to those who see NHS 24 as an emergency service, some people view it as 'like a doctor' and as a more or less direct and equivalent replacement for previous out-of-hours provision, whether that was from their own GP or from a GP cooperative. In some cases this was linked to the previously noted uncertainty about how out-of-hours care is structured and a vague sense that NHS 24 had been introduced as a replacement for out-of-hours GP cover.

James: *I kind ae look as it as if, I'm mebbe wrong but I look at it as if, like NHS 24 is obviously for patients who are like obviously non-emergency or that like, I understand it tells you when you phone them if it's a real emergency phone 999, if it's not hang on the phone, eh? ... And I look at it as if it's like a 24-hour doctor. I'm mebbe wrong but that's the way I look at it, like in the olden days you would phone the doctor durin' the night and the doctor would come out, eh, they used to have, I don't know if they still have it, [cooperative] doctors, [...] that used to be out ae the surgery but I don't know, I think they've done away wi that and it's now NHS 24 eh? I think, I'm no a hundred per cent sure.*

Josie described getting advice from NHS 24 as 'like getting a call back from the doctors' and Maggie said 'it's a bit like havin' a doctor on the end of the phone I guess, ehm, but without havin' to go and bother your GP'. However, it's worth noting that although some interviewees see NHS 24 as equivalent to a doctor's

service, most of them still see it as specifically like an *out-of-hours* doctor. They don't talk about using it in the same way they would use primary care services for routine health matters; rather, most still see it as for things that they consider urgent. In the focus groups with staff, however, there was a fairly widespread perception expressed that some people use NHS 24 as an alternative route to routine primary care. For Hazel, a member of the Patient Participation Forum who is also an NHS 24 nurse, this is both problematic because it has led to increased and sometimes inappropriate demand, but also 'good' because people who may not otherwise seek advice about symptoms may be more likely to access care this way.

Hazel [PPF FG]: *Because initially it was brought online because the GPs weren't going to be working out-of-hours, and it was gonna be there so that patients could be directed to the proper health... avenue. And, it's kinda become a product of its own success if you like because, it's now an access-patients- I've even patients phoning up sayin' 'I don't know if this is appropriate for my doctor but I wanted to speak to somebody first'. Or phoning up for a second opinion cos they don't, believe what their doctor's told them. We've, we've produced another GP surgery for a lot of people. And that in itself shows there's people out there that's probably been worryin' about their health but they haven't wanted to bother their GP but again that could come down to a generational thing, 'I don't know if I should bother my GP about this... GP's busy, eh, is too busy to listen to what I've got to say'. So they phone NHS 24 we're becomin' another outlet for people, which, which is good but it's the way that the whole system's developing, everybody's developing.*

Sandra, who had previously expressed shock that some people within the organisation saw NHS 24 as a primary care service, nevertheless has some sympathy for those who use the service as an alternative route to primary care. She is particularly aware that people can sometimes find it difficult to access appointments, and that doctors and receptionists do sometimes advise people to call NHS 24 when there are no appointments available.

Sandra [nurse- staff FG1]: *And that's why I understand what this person said about it bein' a primary care service, is that, the wee person that can't get to their GP or missed the call in the morning to get the first emergency appointments or, you know, has to go public transport and things like that, not very mobile. You know, they can't get their doctor's appointment and when they eventually get through at 5 o'clock, they're told to phone us, you know, often I think well, d'you know something, you do need to see a doctor,*

you've tried x, y and z for 3 days, you can't see your own GP, why not see a GP in the out-of-hours?

Some of the nurses worked in GP practices or in the community as well as at NHS 24 and so had first-hand experience of poor access to some practices, which Sandra described as '*like trying to access god*', and the frustration this can cause for patients. Sara, who said NHS 24 is an emergency service, has a similar attitude to Sandra in that she understands why people use it as a way to access primary care and the frustration they experience when they are told there are no appointments available. It is clear that although the nurses see some people's use of NHS 24 to access routine primary care as problematic, they also understand the systemic problems which lead to this situation. They are willing to act as advocates for patients and to ensure that they get the care they need, even while bemoaning their 'inappropriate' use of NHS 24.

4.2.3 'Somebody you can call'

Many respondents see the main purpose of NHS 24 as providing advice, although not specifically self-care advice. While some see a role for NHS 24 in helping people to look after themselves or others at home, more usually people said that they look for advice in order to enable more informed decision-making. Often people linked advice-seeking to their own lack of medical knowledge and expertise, and found being able to get advice from someone with clinical training particularly valuable (this will be discussed in more detail in chapter 7). For example, for Caroline, who has small children but also works in a care home, being able to pass responsibility for decision-making on to someone with more expertise is important.

Caroline [mothers' FG]: *They're good to be there because you can just phone for advice, and then they decide if they need somethin' medical or tae see somebody, somebody else. So it is good that way that there is- [...] Cos you just- again it's during the night but- hey-ho we're no nurses!*

Claire, who also has small children, feels the same way:

Claire: *I think it's really good to know that there is somebody you can call, to get information from, and even if they're not goin' to- you can just- [...] I have called them just to get clarity on somethin' before, and it's good to know that if you do ring them they'll give you as much information as they can. And*

they seem to be very pleasant, when you ring them; they seem to want to talk to you. And have a conversation and ask you questions. Which is good, ehm, it's good to know that that background is there, especially out-of-hours. And you can ring them at any time, obviously 24 hours.

ED: *Would you call your GP like that to just get clarity on something or to-?*

Claire: *If... If it was, if I brought, say Sinead to the doctor on a Monday and then if they prescribed me with medication, and if that afternoon I was givin' her her medication and I wasn't sure about somethin' I would ring the doctor's, because it was in relation to something I'd received, but if it was somethin' else, somethin' outside- if it was... somethin' other than that I'd probably ring NHS 24. Because they're at the end of the phone, the doctor that you want to speak to is not necessarily available.*

As Claire's last comment illustrates, the accessibility of NHS 24 is significant. The ability to access trustworthy advice in just a phone call means that some people do feel enabled or empowered to call about things that they don't think are necessarily urgent, and that they wouldn't contact a doctor about.

Irene: *Ehm, I've only used it a couple of other times, you know, but it's usually just, it helps me clear up any questions and particularly at weekends when, you know, you can't get access or late at night when you don't want to be, you know, calling out a doctor for something that's not serious.*

The relative ease of accessing NHS 24 compared to seeking advice from other sources is important to people in both urban and rural areas, although for different reasons (Roberts et al. 2009; McKinsty et al. 2009; Elliot et al. 2014). For those living in remote and rural areas, NHS 24 saves them time because they can have a quick assessment, allowing them to make a more informed decision about whether it is necessary to make the sometimes lengthy journey for a face-to-face appointment. For example, Heather lives in quite a remote area and has 2 small children. For her, being able to find out if further assessment is actually necessary before going to the inconvenience of bringing the children to a clinic or hospital is valuable. Others pointed out that often an out-of-hours doctor is based in a town or city some distance away and a lot of time would be wasted in calling them out unnecessarily if NHS 24 wasn't able to carry out a telephone assessment.

Julie: *Thinkin', as I say again, 'specially here, eh the doctor comes fae, he can come fae [nearest town], he can come fae all ower, it can take you an*

hour to get here, but if you have a phone call, you can have it sorted in 5 minutes, and if I need to go in, we'll just take the car and go in.

Steven: *We can be there before the doctor would come anyway.*

Julie: *Rather than the doctor comin' out here to say somethin' -*

In urban areas, pressures on GP practices seem to be much greater, and NHS 24 saves people time by giving quick answers to questions, and offering reassurance, when they might otherwise have to wait weeks for an appointment with a GP.

Natalie: *I just, I find it's a lot quicker to get advice. It's, ehm, it's obviously, you will end up speaking to someone. Ehm, and sometimes when you do want advice, you want advice right then, you don't want to wait 2 weeks for a doctor's appointment over something which might be absolutely nothing.*

For Natalie, the immediacy of the advice available makes NHS 24 her 'go-to health service', but only for things that aren't 'actual illness'.

Natalie: *So they're now actually my sort of go-to health service if something that I don't think, basically when I want advice. I'll phone them up. If it's something like, you know, like an actual illness like tonsillitis or something I feel that I need antibiotics for, then I'll go to the doctor's, but if it's advice I'll phone NHS 24.*

A small number of people talked about finding NHS 24 staff supportive; for example, Jim said that he thought it was 'good to have support there'. However, support was not overtly mentioned as part of the role of the organisation by any of the interviewees except Angela, who is also a health visitor and so possibly has a slightly different perspective on the role of nurses. Katie said that she relies a lot on health services generally because she doesn't have much other support and she described NHS 24 as 'a great comfort' when her baby was born, but she highlighted a need for greater support and suggested that there should be a separate phone line for mothers because the process of calling NHS 24 feels 'formal'.

ED: *Yeah, how would it be different do you think? Like, what would you like that to look like, or-*

Katie: *Well I'd like it, ehm, like you can phone the health visitors' office, that's really good, and you can just phone them and ask them like, things that seem silly but are actually really important, ehm, and they help you out and they give you advice, but it'd be good if you, it was like that, like 24 hours, like you get to speak to a health visitor or something.*

ED: *Does it feel different when you call NHS 24 then, from calling the health visitor?*

Katie: *Eh, yeah, it seems a little bit more formal, eh, yeah. Mmmhmm.*

ED: *And is that, like, the fact that it's formal, how does that affect you, or how does that make you feel about doing it?*

Katie: *Ehm... it kinda makes you feel that you can't, ehm, phone unless it was something really quite, ehm, serious. Mmm. Mmmhmm.*

What Katie is describing here is a need for 24-hour access to post-natal advice or parenting support, rather than clinical triage. Katie was not the only person to express some discomfort around calling NHS 24 for advice. Lauren, who primarily sees NHS 24 as a way to get a face-to-face appointment, thought it would be helpful to call for advice but was not sure if that was legitimate use of the service.

Lauren: *[...] even if you just want health advice I think you can phone NHS 24 if you're not sure what to do like...about something. Can you? I don't know. If you've got like, a sickness bug or something like that, can you phone them and ask them what's the best thing for me to do right now?*

Claire also showed some uncertainty around calling for advice. While she thinks of NHS 24 as 'somebody you can call', and suggests that it 'should be ok to use it in that way', she is aware of messages suggesting that the service is for urgent care.

Claire: *Yeah. It's not really- the one thing I suppose, it's not really advertised as being, well I don't think it's advertised as being something that you can ring up just to have a chat with.*

ED: *Right*

Claire: *Ehm, I personally, think it's ok to use it, not to have a chat, [laughs] but if you want somethin' d'you know if you want to get somethin' clarified, like on medication or stuff like that. Ehm... I think it should be ok to use it in that way.*

The comments from Katie, Lauren and Claire all show that there is a need and desire for general advice and support and that they see a role for NHS 24 in providing this, but that they are uncertain about whether or not it is acceptable to use it in this way. The 'formal' way that the service is delivered may discourage people from seeking advice, but these participants would do so anyway in the absence of any alternative.

There was a feeling expressed by some of the staff that people have become more accepting of self-care advice and that there is less expectation now than in the early years of the service that people will be seen face-to-face. They suggested that this may be linked to their own growing confidence as individual nurses and as an organisation in giving people self-care advice. Some staff discussed how they feel about calls where people acknowledge that they want advice rather than urgent care, and, as is the case with people who use the service as an alternative route to primary care, they had considerable sympathy for people needing advice or support.

Sandra [nurse-staff FG1]: *I think, at the outset when NHS 24 was first marketed as an advice service, a lot of people still phone up and they'll say 'Oh it's no an emergency hen, I'm just wantin' some advice' and that's all they want [...] and I like those calls because, you know, we're sittin' here very knowledgeable and these people out there, what I think is common sense, as a nurse, is not common to everybody who's not a nurse, you know-*

Mary [nurse]: *I think it's good when they go intae it sayin' look, you know, 'I'm just lookin' for some advice just to tide us over tonight', and that's good, it's a very good expectation to go into the call with. [...] That I think's quite good.*

Importantly, here, the nurses refer to callers prefacing their requests for advice with disclaimers that they are not seeking urgent attention, and downplaying their expectations of care (Hillman 2014) by saying that they are 'just' looking for advice. In this way, calls that might otherwise be considered inappropriate can be reframed as appropriate because the caller has done the work necessary to establish themselves as a responsible and undemanding service user (Hillman 2014). These comments also show that, for these nurses, seeing NHS 24 as being an emergency service is not incompatible with seeing it as being there to provide help and advice.

Although there seems to be a very clear contrast between what is meant by provision of routine advice and provision of help in an emergency, NHS 24 is seen by some staff and callers as being designed to provide both. For example, Irene, who I quote above as saying she used it to '*clear up any questions*' also said that she thought it was only for '*urgent*' things. I asked one of the staff focus groups how they understood NHS 24, given the seemingly contradictory views they had expressed, and their response is revealing:

ED: *I'm just wondering, do you see it as an emergency service and, if so, how does that match up with advice type calls?*

Kathryn [call handler- staff FG1]: *It should be an emergency.*

Jane [nurse]: *Oh I think, I think it could be both, I think it's an emergency service if you need to be seen, if you need to be seen by a doctor that's what we're here for to be able to work out who needs seen, ehm, whereas in a lot of cases we're here to be able to give advice to promote independence to people to look after themselves or, or their dependents. I think it's, I think it's both.*

Sandra [nurse]: *Mmmhmm. [...] But yeah, it's ehm, I think it's both.*

Indeed, it does seem to be both, and a service which can meet the needs of callers regardless of the urgency of their situation would appear to be consistent with the original aims of NHS 24 as a gateway, directing people to the best source of care. However, the fact that both staff and callers feel that NHS 24 is appropriate for some types of calls and not others suggests that having such a broad and undefined remit may have consequences in terms of people's expectations of the service.

4.2.4 Gateway or gatekeeper?

The original aspiration of policy-makers was that NHS 24 would be a gateway to the NHS and a small number of interviewees described it in this way, with Grant actually referring to the service as 'a gateway' for accessing other services out-of-hours. However, some people see it very much as a gatekeeper. The accounts of the nurses make it clear that they often see this as their role; although, as examples discussed in the previous sections show, they sometimes subvert this and become advocates for patients, helping them to use NHS 24 to access care that they can't easily access otherwise.

Some callers also see NHS 24 as a gatekeeper and perceive its purpose as being to 'free up doctors', to 'take the pressure off the doctors' or to 'take the load off doctors'. Steven and Natalie both used the term 'filter' to describe the service:

Steven: *It's for finding out whether you need to take them into hospital, or take yourself in or whatever, or what is basically wrong with you. I think it's just an advisory bit, to filter out the ones that don't need to go to hospital that's gonna waste time.*

Natalie: *I think, I got the impression they were there to take the load off doctors, to try and filter out all the little, not meaningless queries but... like for something, like, you know, take some paracetamol, ehm, that might take up a whole, you know 5 minutes of the doctor's appointment but only thirty seconds down the phone. So, in my mind they're just there to filter off, people who, like hypochondriacs like myself!*

Andy said that he sees NHS 24 as a useful ‘*middle ground*’ between waiting until the GP surgery is open and going to an emergency department. However, for some people, rather than being a middle ground, NHS 24 is viewed as an extra step which represents a barrier to accessing care. In the interviews, some people mentioned that they had found this to be the case in the past, although only Robert had found it to be the case during his most recent call to NHS 24. Robert specifically wanted an appointment, and so his frustration undoubtedly stemmed from the fact that he then had to try an alternative route to face-to-face care. It is interesting that more of the interviewees didn't seem to see NHS 24 as an unnecessary extra step to accessing care, given that almost half of them went on to have further contact with a health professional after being given self-care advice by NHS 24.

4.3 Expectations, understanding and use of NHS 24

As discussed in chapter 2, the idea that NHS 24 promoted itself too enthusiastically in the early days as being available to anyone, for any reason, at any time, fed in to the often expressed idea that the organisation has ‘*created a monster*’. From speaking to staff involved in clinical governance it appeared that many complaints and expressions of dissatisfaction from both the public and other providers arose from expectations going unmet. It was recognised by some people I spoke to within the organisation that NHS 24 as a service has changed a lot since its introduction in 2002 and that there is (and has been) no clear message about its purpose, as illustrated by the range of views discussed so far. In this section, I consider how expectations of the organisation and people's understandings of it as being for emergencies, for urgent care or for advice may influence how people actually use NHS 24. I also show the difficulties that people experience in assessing the urgency of their symptoms and how this makes it much more difficult to ‘know who to turn to’.

4.3.1 Expectations

The extent to which people's expectations are met by an out-of-hours primary care service is a key determinant of satisfaction (McKinley et al. 2002). When people don't have a clear understanding of how a service works and what it can provide, their expectations may not be matched by what is actually delivered. Some of the participants in the staff, PPF and CGPP focus groups in particular were highly critical of the level of expectation people have about what NHS 24 can provide. This was linked to generational change, a rise in consumerism, and a sense of entitlement as well as acknowledgement that the capacity of the service to meet people's expectations is restricted when it experiences pressure due to rising demand.

Sara [nurse- staff FG2]: *I think that then, eh, the public have, I think a lot of the public have quite a dim view of NHS 24 and the service that it provides because, again I think society now, thanks to lots of patient charters, ahm, 4 hour waits in A&E, everything geared towards making the patient journey better, which is right, you know, but it's turned around and bit us on the bum because it's now putting a huge demand on our services, when we just can't provide, and we're in a situation now where, you know people are expecting, and a lot of people know what they're entitled to as well, so you know if you try and say something they'll know, and they, you know they've been there before they know the right things to say, but, we have to then, eh you know say to these people, you know, this isn't, appropriate, and ehm, you know you open yourself up to abuse. You know, and, it's not gonna get any better unfortunately I can't see, you know, it's just-*

Joanne [call handler]: *I think it's gonna get worse actually.*

In these focus groups there was also a lot of discussion about people's use of NHS 24 out-of-hours as a route to primary care because it fits into their lifestyles. This was linked to working patterns and the difficulties of taking time off during the day to see a GP. Some participants thought that this was more prevalent amongst young people, but others considered that such behaviour could be seen in all working-age people. It was also linked to the idea that in a '24-hour society' people expect to be able to access whatever they want, whenever they want it, including health care.

Annabel [nurse- staff FG2]: *But they're of a generation where they see the GP and NHS as a service.*

Simon [nurse]: *Mmmhmm, yeah.*

Annabel: *It's not something particularly special; it's not different from goin' to your bank. It's a service. And there's that generation who will stand back and say well actually, doctors are great, nurses are wonderful, but the bottom line is you're a service. You're employed by the public, for the public. So if we're goin' to go down that road then I should have access to the service, 24, because NHS are sayin' they provide a 24-hour service. And I think it's that generation that are comin' up that see it as a, business, as a service-*

Sara [nurse]: *Well, I think-*

Annabel: *-not as somethin' really special, and, only go there if you're kind of, crawling there, you know.*

Annabel also noted that people now realise that GPs working in PCECs out-of-hours are being employed to work those shifts; it is no longer the case that a GP is being woken up at night, and this makes people feel more comfortable asking for appointments out-of-hours. The tone of discussions about this was generally quite judgemental, with little acceptance that this may be a rational perspective. However, Sara put forward the interesting view that perhaps the way that people use the service shows where the demand is, and that the organisation needs to respond by changing its own remit and ways of working.

Sara [nurse- staff FG2]: *No but I think, to be fair though, that you can look at that in, in 2 ways. Inside looking out, we know that we have a certain, remit, ok. We have to see people that, who- symptoms not, not you know that the symptoms warrant an appointment, ok, not because they can't get there from work or whatever. But then you've got that argument of, well the GPs provide a service and, so really somebody needs to cover, health, eh, for 24 hours. The GPs do it in-hours; we do it out-of-hours.*

Annabel [nurse]: *We do it out-of-hours.*

Sara: *So, then, do we need to look at it and say well, do we need to change our remit then and say well actually we're not emergencies only, and we give appointments-*

Annabel: *We're just an extended GP service. Mmmhmm.*

Sara's suggestion here that, rather than trying to persuade people to conform to ideas of appropriate use, the organisation should clarify its role and adapt to meet the expectations of the public, shows recognition that 'inappropriate' service use can be conceptualised as a systemic problem linked to issues with service provision and access rather than as a result of the failure of individuals to access the correct service (Chew-Graham et al. 2004).

There was little evidence in the individual interviews that people used NHS 24 out-of-hours for convenience. Most interviewees told me that they called NHS 24 out-of-hours because that is when they became worried about symptoms. However, in the focus group with mothers of young children, Karen admitted that she sometimes uses NHS 24 because it's preferable to seeing a GP at her local surgery due to access problems.

Karen [mothers' FG]: *I'll wait, that sounds bad, I tend to wait 'til after the GP surgery has closed if I know ma kids aren't well, because they'll get treated for what they needed when they're needed.*

Caroline: *It's quicker.*

ED: *So you just, prefer to use the out-of-hours service?*

Karen: *I do use the out-of-hours service before I'll go to my own GP.*

ED: *Is that because you've tried to use the GP before and-*

Karen: *GPs are hopeless.*

Holly: *9 times out of 10 eh, well 10 out o 10 you cannae get an appointment. [General agreement]*

This suggests that use of NHS 24 for convenience is directly linked to unmet need in other parts of the health system. The rationality of this course of action is often then confirmed when people get faster and more efficient access to care via NHS 24. However, some of the staff believe that this raises people's expectations even further and influences the outcomes they expect on subsequent occasions. Some staff see the flexibility of NHS 24 and its willingness to accommodate the requirements of callers, in a way that other services wouldn't, as problematic. For instance, in some health board areas NHS 24 can arrange for transport by taxi to a PCEC if patients have no other means of transport. Because this wouldn't happen during the day, it is seen as increasing the likelihood that people will choose to use NHS 24 rather than contacting their GP surgery in-hours. Likewise, because NHS 24 has a policy of calling people back if they get cut off, the staff had a sense that some people expect to be called back if they have no credit on their mobile phones (this was prior to the introduction of the free 111 number). The way that staff are constructing patient expectations as the result of how the service operates is particularly interesting here,

as is the role that they see for themselves in managing, and challenging, these expectations.

Annabel [nurse- staff FG2]: *You know whatever-, so they kind of delay it I suspect, some of them, because, they'll never get transport to their own GP surgery, but some areas will give them transport to their out-of-hours!*

Sara [nurse]: *Yeah*

Joanne [call handler]: *Same as when they've no money on their phone either!*

Annabel: *And I think this is-, I'm not quite sure why we're givin' transport sometimes to patients, I just-*

Sara: *I think it'd be better if we just didn't.*

Simon [nurse]: *If they didn't give transport-*

Annabel: *-because I think that's changed people's expectations, they know, that they can get transport-*

Simon: *Expectations, people'll say, you know-*

Sara: *Or they'll ask! They're not, they're not shy, they'll actually ask. You're talkin' about young people, young, and, and some nurses don't want to have that conversation, so to challenge that, when they say, 'Oh well I'll need transport' and then some nurses will say 'Ok that's fine'. If you're like me, and I'm sure like the rest of us, we would say, well why, why?*

The nurses reported that repeat callers in particular have an expectation that they will always get an appointment, or even an ambulance, because that's what has happened on previous occasions when they have called NHS 24, and that this can make it more difficult to convince them that they don't need to be seen. Interestingly, some of the staff linked this to risk-aversion on behalf of others working in NHS 24, and suggested that if they were doing assessments properly people would not be seen unnecessarily and would become more used to being given self-care advice. The views expressed by staff here clearly evoke the gatekeeper role.

There was a notable difference between the claims that were made by participants in the focus groups, and to a much lesser extent in the interviews, about what 'other people' expect from services, and what interviewees told me that they had actually been expecting when they called NHS 24. When talking about other people, participants claimed that 'young people' want to be seen more quickly and aren't prepared to wait or that 'older people' expect the doctor to come out to the house,

and so on. In reality, all but 5 of the interviewees in my study told me that they had been expecting to be given advice or reassurance when they called NHS 24 and that what happened during the call met their expectations and was satisfactory. Of those who weren't expecting advice, Alison expected to go to hospital, while Angela and Andrea had both expected to be given out-of-hours appointments; however, all 3 said that they were happy with the outcome of their calls, because they felt reassured that a face-to-face assessment was unnecessary at that point.

James was ambiguous about whether or not he had been satisfied because he wasn't seen face-to-face, but he was also ambiguous about what his expectations had been. On the one hand, he said he thought that there was nothing that could be done for him, but he nevertheless called NHS 24 again the next morning and then went to A&E rather than waiting for a call-back. Of all the interviewees, only Robert expressed clear dissatisfaction with his call; he had expected to be given an appointment and instead was given self-care advice. This led to him saying that he wouldn't use NHS 24 again. However, it was the first time that he had used the service, he had heard negative reports about it from others, and he didn't have a clear understanding of how it works. It seems therefore that most people in this study did not have unrealistic expectations of NHS 24 and that their experiences were positive; Robert's experience suggests that a limited understanding of the service can lead to unmet expectations and dissatisfaction.

4.3.2 Knowing who to turn to

It is notable that when describing their understandings of NHS 24, many participants expressed uncertainty. As the interview extracts presented in this chapter show, people used terms like '*I think*', '*I'm not sure*' and '*I might be wrong but...*' when describing what the service is for, who they spoke to when they called, and when NHS 24 is available. Interviewees also expressed considerable uncertainty about when calling NHS 24 is the 'right' thing to do. Previous research with callers to out-of-hours services in England has identified that people often experience anxiety and guilt around their decision to make the call (Richards et al. 2007); similarly, it is clear from the accounts given by the respondents in this study that for some people

uncertainty about their understanding of NHS 24 leads to anxiety about using the service. For example, both Maggie and Laura were confused by the recorded message they heard when calling NHS 24, which to them suggests that it is an emergency service, and they found it off-putting when calling for advice.

Maggie: *When you phone up it sounds as though this is for dire emergencies only, and to me, I would phone ma doctor or an ambulance in a dire emergency, ehm, or go to A&E [...] I mean to me it would be better if there was almost like 2 strands of NHS 24, but how do you know if it's serious or not? And even the people you speak to don't always know; and you know you hear these awful stories [...] Maybe if... it might save more people going to GPs or going to Accident and Emergency if NHS 24 didn't sound quite so much like it was an emergency service only. Ahm, because when I spoke to the person I spoke to, and I felt so silly, I was kinda, 'I feel really silly, I feel like I- you know I don't want to take up your time but' ... Ehm, and I think maybe that, for other people that might save them goin' elsewhere if they didn't feel like 'This is only for emergencies anyway, maybe I should just go down to A&E'. [...] So I think it perhaps, should feel more accessible and ehm, maybe less like you're wastin' someone's time.*

Laura: *Ehm... well... My understanding of it is that's it's for... ehm, emergencies. And you could argue I phoned and it wasn't an emergency. I'm aware of that, ehm... so, but I- I would say I use it as- [...] well I have used it as a port of call [...]*

ED: *So there's kind of a, a slight disparity there between sort of seeing it as being for emergencies but using it for something that's not.*

Laura: *Yeah. Uhuh, because when I was on the website, [...] I think it says on there somewhere about for emergency use, and am I right in saying when you phone does it say this is for, this number is for emergen-? And every time I hear that I think oh, this isn't an emer- do you know what I mean? This isn't an emergency as in, child's not breathing or someone's been knocked down, so, in that sense it's not an emergency. But, from a parent's point of view what else would you do? If it's a Sunday night, you know. So... Yeah there's a, there's a... dilemma there, a bit of a quandary.*

Maggie described how she 'felt bad' contacting NHS 24 because her cut feet and swollen ankles were clearly not an emergency. However, it is evident from Maggie's account that she was worried and that she benefitted greatly from being given advice and reassurance.

On the other hand, seeing NHS 24 as an emergency service may lead people to use it in situations which require an emergency response. A number of respondents said

that they had previously called NHS 24 in situations which were assessed as suitable for an ambulance; for example, both Holly and Gail had called about head injuries in very small children and both had been sent an ambulance.

Holly [mothers' FG]: *See I did, when Caitlin fell off the trampoline on to the concrete backwards and sma- smacked her heid, it was NHS 24 I phoned and the minute I said she'd hit her head on concrete they sent an ambulance for her to A&E...*

Gail: *Craig, when he was 5 months old, fell doon a spiral staircase.*

ED: *Right?*

Gail: *And cracked his heid off it. Right? And, well ma first thought was to phone NHS 24 because I thought well, you know it's, I dunno what to do! You know it was just panic, because at 5 months old, 'Oh my god, his head's still soft, you know have I done- is there damage done?' You know, it was just panic.*

I asked Gail why she hadn't called an ambulance instead of NHS 24 on that occasion; her response highlights both the difficulty of assessing the urgency of symptoms and an awareness of the moral imperative not to waste resources and not to take action that isn't 'allowed'.

Gail: *Because I dinnae know how serious things are. I just, I dinnae, I'm-like, I would need someone to tell me that that was serious enough to phone an ambulance, because I wouldnae want to waste an ambulance time. You know there's people out there that- I can drive. I could drive them til the hospital if that was the case. But I wouldnae know, whether that was allowed or not, I wouldnae know that that was- it's basic knowledge I need. I just need to know what's ok to phone NHS for and what's not. I would never even think to phone an ambulance. Like, straight away.*

Other interviewees also identified a lack of ability or confidence to assess the urgency of symptoms as a reason why they would call NHS 24 in an emergency.

Many considered that calling an ambulance is too extreme a reaction for most situations, and they again highlighted awareness of pressure on resources as part of their reasoning. For example, Alison described becoming hypoglycaemic and said that she had thought that she was going to die, but when I asked why she hadn't

phoned an ambulance she downplayed her symptoms and suggested that someone else might have been in greater need:

ED: *And what made you think- cos you said you were quite scared and you thought you might need to go to hospital, was there a reason why you called NHS 24 instead of an ambulance?*

Alison: *I just phone the NHS 24 all the time, I dinnae think of callin' an ambulance.*

ED: *Yeah.*

Alison: *In case it, you know it wasnae emergency, somebody else would need the ambulance.*

ED: *Yeah so you didn't feel like it was really urgent?*

Alison: *No, no. I wouldn't, even when Karen took asthma attacks when she was young, I never phoned an ambulance, it was always NHS 24.*

While some people think that NHS 24 is for emergencies and some think that it is not for emergencies, almost all think that it is not for 'minor things'. In the focus groups, I asked people what they considered to be minor symptoms or minor illnesses. Staff participants found it quite easy to list a whole array of symptoms which could be categorised as minor, whereas lay people found this question much more difficult, and generally stuck to things like coughs and colds. Lay people also tended to have a much more nuanced and contingent view of what is minor, arguing that definitions of 'minor illness' depend on the individual experiencing the symptoms and the particular circumstances. Factors considered to affect whether or not something is minor included the age of the person who is unwell; the time of day; how much someone is able to tolerate pain or discomfort; and their level of understanding of their symptoms.

A number of interviewees alluded to this in their accounts; for example, Tina had been quite critical of people who expect a doctor to visit them when they have an illness such as flu but when I questioned her further on this she highlighted that it is difficult, for both lay people and NHS 24 staff, to know if minor symptoms are actually a sign of something worse.

ED: *Yeah, no just when you were saying about doctors not kind of coming out for people with the flu and things like that, it just-*

Tina: *Yeah that's crazy. Aye. But then again, it could be more serious, it could be pneumonia, you don't know, you know. I've had that pain theres, so. [Clears throat]. It's a hard call isn't it, to think. I think for little things like me, takin' the wrong tablet or... you know, what, what temperature should my baby be? What should ma blood pressure be? You know, I think it's high, cos we've got a machine we use, whether it's low, or I'm not sure? Or, you know if there are things like that it's-*

ED: *Those are the kinds of things that it's, that you could ring NHS 24?*

Tina: *I think it'd be good for that but... but, for, I'd be worried that there was somethin' seriously gettin' missed, you know that somebody'd phone up and say 'Ma child's, got a really high fever' and it could be meningitis or you know, whoopin' cough or, you think well, just Calpol or whatever I don't know what they give now. You know, self-administered and it could be somethin' more serious you know.*

There was some recognition from staff that it can be difficult for lay people to assess a symptom by themselves. For instance, in the example used by Hazel (a nurse and PPF member) she acknowledges that the right thing to do in the case of a cut can depend on a number of variables.

Hazel [PPF FG]: *You know, a cut. You're not sure, well, well is it a cut? I mean what do I do with it, do I cover it up? Or, does it look deep, is it not deep? If somebody's not clinically, eh, minded th- you know, does that need a stitch? Is it, you know, I shove a plaster on it, it's still healing does that mean that it needs a stitch? But it could just be a small minor cut you know but it might still need a stitch so, it doesnae need to go to Accident and Emergency, you don't need to go away, 'Oh I'm not gonna sit in Accident and Emergency for hours' but you just want some advice on how, you know should I keep it like that or do I need assessment?*

The idea that lay people can find it difficult to assess the severity of their own symptoms will be discussed more fully in subsequent chapters. What is relevant here is that a lack of ability to assess symptoms can lead to uncertainty about the best course of action in an illness situation and anxiety about calling NHS 24. This is compounded by poor understanding of the health system and the availability of a number of possible routes to care. In the focus group with members of the CGPP, this was again linked to education about how services work but, as Jack acknowledges, when people are ill or worried doing the right thing may become much less important than getting help quickly.

Elisabeth: *That's the thing, when you're askin about how people should or would react tae a minor illness, or any other illness for that matter, they have to be able to define where to go anyway, and if that education isnae really put out there in the right manner, they'll no know what to do, they'll be in a total quandary, and if you batter them, their mind with too much information, you know like you've got NHS24.com, you've got the NHS Direct, NHS 24, you know all the different-*

Jack: *That's right*

Elisabeth: *-components, where do I go? You know-*

Jack: *And if you're ill Elisabeth you don't, you don't care aboot NHS-*

This was echoed in the interview with Matthew and Ingrid, when they discussed the difficulties of assessing how serious an illness might be and deciding the right service to contact. Ingrid argued that one single route to accessing help would avoid the need for lay people to assess their own symptoms.

Matthew: *Calling an ambulance I think is the one thing that puzzles some people, because at what stage are things serious enough, you know I tend to think, well if you're lying on the ground screaming with a slashed leg you call an ambulance, you know, but if you've just got a bad pain you don't, though the bad pain might in fact be medically more serious [laughs] ehm-*

Ingrid: *This is the trouble with not being medics you know, I mean the medical profession expects people to know something, and people don't, eh, that's what we need them for, ehm, you know, you're saying is it appropriate to contact this or that service I mean, you know, if, if you get something in Latin, appendicitis, I mean, ehm, just imagine the book you would need, the size of book to say if this, that and the next thing is wrong with you [...] Eh, it's much better to say 'Well, if you take ill you phone the doctor' and if he happens to not be there because he's gone home for the day then, some telephone should be put on to somebody else who is there and can deal with it and that's the only way to make it work. To get people to phone this or that or the next thing, it's hopeless, you know, people can't find out what they're doing and they get confused and they lose confidence [...]*

The inherent difficulty in expecting people to assess their symptoms and to choose which service to access based on this assessment is neatly summed up by Lauren:

Lauren: *I don't actually, I think, I don't think there's like, a defined line between 'You have this problem so it's A&E, you have this problem so it's NHS 24'. I think it's just like, personal feelings on the situation at the time.*

Her comment encapsulates the views of many participants, either explicitly stated or implied, that their decisions to use NHS 24 depend on their own feelings about how

urgently they think they need help or advice, and the immediate options available to them for accessing that help, rather than any awareness of the sorts of problems that NHS 24 is for. This echoes the findings of Houston and Pickering (2000), who note that for some parents, in some circumstances, the dilemma about whether or not calling the GP out-of-hours was the right thing to do was resolved by just making the call. This was triggered by an ‘emotional response’ combined with the particular circumstances of each individual. One of their participants claimed that she didn’t even think about what service she was calling, she just thought ‘we need help’ (Houston and Pickering 2000: 238).

In practice, this means that people are likely to use NHS 24 in a way that suits their needs in a particular situation. However, for some people, worry about whether or not their use of NHS 24 fits with its purpose creates anxiety about the appropriateness of their service use and this may present a barrier to access.

4.4 Summary

This chapter has illustrated a range of understandings of the organisation and purpose of NHS 24 on the part of both staff and service users. It has shown how these understandings influence people’s use of the service and how their expectations and use of the service also influence the way in which it is provided, as staff respond flexibly to manage these expectations.

There is sometimes confusion about how NHS 24 links to other services; while most people differentiate between NHS 24 and their GP, many do not distinguish between NHS 24 and locally provided out-of-hours primary care. The significance of this is that callers may have unrealistic expectations of the care that NHS 24 can provide and there could also be reputational damage to NHS 24 if people are dissatisfied with their onward care. Callers may also be unaware of the level of clinical training of the person they speak to when they call NHS 24. Some accounts suggest that this is not very important, but it becomes relevant if people are not sure why they are being passed from one staff member to another. In addition, there is no consensus on whether NHS 24 is a 24-hour or out-of-hours service, with repercussions both for

how it is used and how the service is provided, which is different in the in-hours and out-of-hours periods.

Section 4.2 demonstrated the different understandings of the purpose of NHS 24, with some staff and service users considering it to be an emergency service. Others likened it to a primary care service, albeit an out-of-hours service rather than an extension of ordinary GP provision. Still others see the service as ‘somebody you can call’ for general advice and reassurance. There were also differing views on whether the service is a gateway, enabling access to care, or a gatekeeper, filtering out ‘time-wasters’. These varied understandings influence people’s expectations of the service that NHS 24 provides, or should provide, and there are difficulties in knowing which service to turn to when there is no clear boundary around the categories of minor, urgent and emergency and no consensus on which of these categories of care NHS 24 is designed to deal with.

How people understand NHS 24 has implications for how we conceptualise its place in the context of the health system. Those who see it as an emergency service, or as ‘like a doctor’, may be more likely to use it in the same way that they use other services in the professional sector. However, for those who see it as ‘somebody you can call’ for advice and support, it may be an alternative to the lay care provided in the popular sector. The fact that it is seen by some staff and callers as ‘both’ an emergency service and a low-threshold advice line suggests that the organisation lies at the boundary of the popular and professional sectors and can be used by people in ways that meet their particular needs at any given time. However, if a caller’s view of the service doesn’t match with that of the professional providing their care they may have to do significant work in order to construct their call as appropriate.

5. Risk and reassurance

When interviewees talked about the symptoms which had led them to call NHS 24, it was notable how frequently they recounted not having felt able to assess how serious those symptoms were, or might be. While a small minority knew the cause of their symptoms and the likely outcome if no action was taken, for most interviewees the symptoms could be seen as potentially indicative of serious illness. Although most interviewees did not themselves use the term ‘risk’ in their accounts, I have found that it is a helpful concept to draw on when making sense of the ways in which people talked about their uncertainty and anxieties about symptoms. It is, however, a difficult concept to use because of its dominance in sociological theory and the very specific meanings which have become attached to it. Discourses about environmental or lifestyle risks (Lupton 1993) and even corporeal or ‘embodied’ risk (Kavanagh and Broom 1998) have clear limitations when it comes to understanding the sense of vulnerability people feel when actually experiencing unfamiliar or potentially dangerous symptoms. However, it is this very ‘potentiality’ (Rigakos and Law 2009) that makes the concept of risk a useful one here. I use it to explore the liminal state wherein symptoms are present but it is unclear what these symptoms *mean*; they may be completely benign, but at the same time they may be seriously threatening. I explore this here in the context of attitudes to and awareness of risks more generally.

As might be expected given people’s anxieties about symptoms, reassurance also emerged as an important theme in the interview data. Reassurance is a key element of patient-health provider interactions (Donovan and Blake 2000) and it has been highlighted in previous studies as a primary need reported by parents when seeking advice about symptoms in children (Neill 2000). Almost all of the interviewees in this sample said that they wanted, or expected to be given, reassurance when they called NHS 24. For some people, seeking reassurance that symptoms were not dangerous or that they were ‘doing the right thing’ was the explicitly stated purpose of their call (when asked in the interview), although this may not necessarily have been communicated during their consultation (Barry et al. 2000).

This chapter offers an analysis of how perceptions of risk lead people to seek reassurance and how calling NHS 24 can be a way of managing or mitigating risk. The chapter also explores how calling NHS 24 can be experienced as reassuring, or not. Attention is paid to the impact of the call structure and how asking ‘enough’ questions or the ‘right’ questions can serve to reassure callers that a thorough assessment has taken place. In particular, the ‘worsening statement’ seems to have a significant effect in both reassuring people that they can access further help if needed, but also that they have done the right thing in calling.

5.1 Risk

This section explores how a sense of risk can be introduced when symptoms are unfamiliar, or when they are similar to symptoms that have developed into something serious in the past. Calling NHS 24 can be understood as a way of mitigating this risk or passing responsibility for the risk assessment to somebody else. I also discuss interviewees’ awareness of public health messages that may have raised their concern about certain symptoms (Kai 1996). Although interviewees did not usually refer to these messages as heightening their anxiety at the time they called NHS 24, many of their accounts are shaped by risk discourses (Lupton 1993). For example, there seemed to be a widely held view that small children and babies are at particular risk and there were also quite a lot of (implicit) references to pharmaceutical risks (which will be discussed further in chapter 6). I conclude the section with a discussion of organisational and professional risk-aversion and how this may influence illness behaviour.

5.1.1 A symptom could be or become serious

One of the factors which led many of the interviewees in this study to call NHS 24 was a worry that the symptom they (or the person they called for) were experiencing might be indicative of a serious illness, or might develop into something worse. This worry was often exacerbated by a lack of familiarity with the symptoms. For example, Peter said that he hadn’t been too worried about his 3 year old daughter’s earache until his brother-in-law mentioned during a chance conversation that he thought earache could be a symptom of something serious.

Peter: [...] someone mentioned, I think it was ma brother in law, ehm mentioned that it could be sorta, I can't remember exactly, but diabetes or somethin' like that, you know it can be a symptom, sore ears in young kids can be a symptom of somethin' more serious, you know a sign of somethin' more serious, ehm. So that's the reason I phoned NHS 24, just to get peace of mind really.

It was only later in the conversation when his wife Anna mentioned meningitis that Peter remembered that was what he had been worried about. Anna, who appeared to be more familiar with earache, was somewhat surprised that this is what Peter had been worried about and by his decision to call NHS 24.

Peter: Mmm, aye meningitis, that's what Chris had said about the ear infection, in young children it could be meningitis. It wasn't was it!

Anna: Most of the time it's just ear infections.

When Heather went on the internet to look for information about her son's swollen groin, she discovered a range of worrying things that it could be indicative of such as 'twisted testicles' and 'hernias', prompting her to seek further advice. Heather was clear that she thought her call probably wasn't an urgent one, but the potential implications of not seeking help were serious enough to lead her to call anyway.

Heather: Cos I knew as well I was phonin' them but it probably wouldn't be, that urgent, it was just somethin' I wasn't sure if I should leave or not, ehm, cos apparently if it's twisted testicles there could be long term damage, ehm, need operations and things, so that's mainly why I called, cos it could be serious.

Likewise, Maggie was fairly certain that her cut feet and swollen ankles were not serious, but she thought that if she hadn't sought advice from NHS 24 she might have panicked and later convinced herself that they had become infected.

Maggie: I would probably have talked myself into it being some dreadful disease that I'd picked up on the streets through ma ankles or something, ahm... and eventually I think I would've ended up probably going to A&E if they- the swelling did go down because I was doing the right things, but if it hadn't I certainly would have probably ended up going to A&E...

Even when people were reasonably sure that they knew what a symptom meant, they sought advice if there was any doubt at all, particularly if getting the diagnosis wrong could have serious repercussions.

Natalie: *I think I, since in my mind I'm quite a healthy person, when things do go wrong I do have a tendency to- I mean obviously if it's something that I expect like, you know just a cold or a cough and that, absolutely fine. But, like a passed out husband, or anything to do with my eyes, anything that I feel out of my depth with, ehm, and anything that I f- I guess when I kind of think that maybe I could just take some paracetamol, but it could be a lot worse, I'll phone them up.*

These accounts demonstrate how an awareness of the potential presence of 'something serious', even when the actual symptoms are not particularly severe, can lead people to seek help and reassurance as a way of managing their uncertainty.

Even when dealing with familiar symptoms, unusual severity or not feeling better within an expected timescale could trigger doubts about the initial interpretation and introduce the possibility that in fact a more serious illness was present. For example, Andy had flu-like symptoms which developed into diarrhoea and vomiting and he had been managing his symptoms with self-care; however, the unexpected duration of the symptoms was one of the factors which led him to seek help.

Andy: *I think as well the fact that it had been 5 days by that point and there'd been no, eh, let up in the symptoms, and I thought after 5 days I would've expected to maybe feel a bit better. So, I phoned just to make sure that there was nothin' more serious as well that could be possibly wrong.*

The age of the person experiencing symptoms is another factor that can increase a sense of risk. Laura was fairly sure that the spots on her one week old baby were chicken pox, as her son had just recovered from the illness. However, she was not confident in her diagnosis because she had previously been told that the baby was unlikely to get chicken pox. Her worry was heightened as the baby was so young.

Laura: *I thought that's what it was, but because I was told by the midwife it was very unlikely she would get it, I thought well it might be something else, ehm, so that's why I phoned. And because she was so tiny, ehm, yeah, uhuh.*

Similarly, for others who had called about small children, the idea that infancy can be a dangerous time was commonly alluded to. Tomasz and Irena both suggested that their need to seek advice quickly when their one year old had a high temperature was

largely due to the age of the child. They both said that they would not have sought help as quickly had it been an adult who was ill.

ED: *But it's quite different when it's the baby?*

Irena: *Yes obviously isn't it cos you feel, the babies they can go down very quickly isn't it, if they dehydrate or they have high fever or anything so it's, you know at that age almost everything could be pretty dangerous so, you know, with the baby you wouldn't want to wait for things to develop, you don't want things to develop really, mmm.*

A number of mothers explained that the idea that you should never take risks with young children had been impressed on them by health professionals. Irena said she had been told by her health visitor not to wait if she was worried about illness in her baby but just to go straight to her GP. Similarly, Jodie had been told by health visitors during her ante-natal classes that 'you do not *take risks with young children*' (her emphasis). I asked her and Grant if that message had made them more anxious about a baby being at risk.

Grant: *Maybe not more anxious but certainly more...*

Jodie: *I would say more aware.*

Grant: *Aware and...*

Jodie: *More conscious of changes, ehm...*

Grant: *Maybe more willing to contact-*

Jodie: *Yeah.*

Grant: *-make contact with health services earlier than, may have otherwise.*

Jodie: *Yeah. It's almost like, I know if-*

Grant: *Open the door.*

Jodie: *-if you notice anything or are concerned about anything, ehm, don't think you're wasting anyone's time. That was more, that- I would say that's what I took from it more than anything else. Ehm, you're better to get it checked out when it's a tiny person.*

Grant: *Yeah.*

Jodie: *Because, because things can change so quickly, ehm, in an infant and that's, that's definitely ehm, that's definitely kind of... It was more that it's, if you like it was a wee green card.*

What is notable here is that seeking help about a child is seen as more legitimate than seeking help about an adult; the phrases 'open the door' and 'a wee green card'

suggest that the fact a child is involved allows Grant and Jodie to negotiate access that might otherwise be denied.

In some cases, there were additional risk factors which made symptoms more worrying than they might otherwise have been. For example, for Debbie, aside from the scariness of the open sore on her leg, there was an additional worry as she had a varicose vein near the affected area which she thought might bleed if the wound got any deeper. Tina found mixing up her anti-depressant medication particularly distressing because she feared a recurrence of suicidal thoughts and for Natalie a nosebleed was more worrying than it might otherwise have been because she was taking a new contraceptive pill and also has anaemia. Natalie's worry was further compounded when she read the patient information leaflet accompanying her pill and realised that high blood pressure could be a side effect of the medication and that the leaflet advised seeking medical advice.

Natalie: Ehm... I think, well for the reason I phoned them up it's because I did realise that it was one of the symptoms that 'If this is happening to you, phone up someone, or get in contact with your medical practitioner', so I just did what they said.

Natalie later revealed that she had thought her nosebleed might have been a sign of extremely high blood pressure and that she had been worried about the possibility of a brain haemorrhage. In this case information compounded rather than alleviated her sense of risk and led her to consider the most extreme outcome.

It is clear that the types of illnesses that people were worried about when experiencing symptoms ranged from very specific and high-profile risks such as meningitis to the much vaguer spectre of 'something worse', but regardless of what the danger was perceived to be, it inevitably raised anxiety and, in these cases, led to help-seeking.

5.1.2 Experiential knowledge of symptoms

A number of people explained their worry that symptoms could be a sign of something more serious by referring to a time in the past when they had experienced similar symptoms or by talking about someone they knew (or knew of) who had

experienced similar symptoms which were serious. For example, Irene's partner called NHS 24 about Irene's diarrhoea and vomiting and she thought this was probably because he had recently been hospitalised with Norovirus and was worried that her symptoms could lead to the same outcome. Similarly, Robert was worried that his stomach pain might be a recurrence of a previous ulcer because the symptoms felt the same to him, even though initial medical investigations at the time of his interview had not so far confirmed his suspicions.

Robert: *But I had, I had an ulcer a long time ago, ehm, and it was cured with triple-x treatment. Ehm, and it never bothered me, it was 20 odd years ago it's never bothered me since, but I've a sneaky feeling that's what it is.*

ED: *Ok does it feel to you like it's the same?*

Robert: *The symptoms are the same, ehm, but not exactly the same, I don't know, the ultrasound's showed up a cyst on ma kidneys, on one of ma kidneys, which is a bit worrying but they took blood tests as well and that eradicated anything significant there, so it's, doctor reckons 20 per cent of the population have them. They don't do any harm. And that's where we're at at the moment.*

ED: *Right, so you're still waiting to find out what it might be.*

Robert: *I've a sneaky feeling it's a recurrence of that ulcer.*

ED: *Is that what you thought straight away when you had the pain?*

Robert: *Yeah, that was, soon as I- but the doctor thought wi the curry, and the boiled eggs full of cholesterol, ehm that was a sure sign, or a point towards kidney- eh, gall stones.*

ED: *Right.*

Robert: *Gall bladder and potential gall stones, blockin' the tubes. But it wasn't, the gall bladder was quite clear. So yeah, we're still waitin' on diagnosis so to speak.*

Tracey had also previously experienced similar symptoms to those that led her to call NHS 24 and a serious outcome in the past raised her anxiety on this occasion.

Tracey: *[...] well I was kinda worried- the last time that I'd actually had tonsillitis my throat completely closed, and I ended up in hospital, ehm, so I was just kinda phonin' to see what they thought was best, if you know what I mean? Ehm, because I couldn't keep ma medicine down, I was just a bit panicky.*

Even though Tracey claimed that she doesn't often visit her GP, she said that because of her past experiences of tonsillitis she is inclined to seek help more quickly for throat symptoms. As with other interviewees, Tracey's account suggests that her call was prompted by what she thought *could* happen rather than what was actually happening.

When Ingrid experienced pain in her upper leg, she and her husband Matthew were worried because a neighbour had once told them about having had a similar pain and thinking it was a blood clot.

Ingrid: *[...] and we were really worried, cos the neighbour was telling us she'd had a dreadful pain in the leg, and she knew exactly what it was and it was NHS 24 and bububub off to hospital, because it's a clot and that's what killed her mother! And I can just remember her sitting and telling that [makes panicked noise] so we called NHS 24.*

While Ingrid and Matthew were unsure about the actual outcome of their neighbour's illness, and whether or not it had in fact been a blood clot, what they did recall clearly was her panic and the implication that leg pain can be a serious symptom.

Ingrid: *You know, it was NHS and then it was away because she was sure that's what it was, now whether it was or not I don't actually know, I think it was, I mean there was some-*

Matthew: *But I mean she had her hip operated on so-*

ED: *Ok, so that was something that had happened a while ago, and it was just in your mind?*

Matthew: *Yes, it was just, the same thing, so you're beginning to think, well, no it's not just a nerve, it could be something serious-*

Ingrid: *It could be something rotten, that was just what absolutely panicked us, well I panicked-*

Matthew and Ingrid are in their seventies and in their interview they described how they generally accept aches and pains as part of getting older. In this instance, the unfamiliarity and severity of the pain, combined with their recollection of their neighbour's story, led them to doubt their initial instinct that it was '*just a nerve*' and to imagine something more sinister. '*Panic*', used by both Tracey and Ingrid here to describe how they felt, was a term also used by other interviewees, suggesting that

although ‘fear’ may cause people to delay seeking help (Smith et al. 2005), panic may be more likely to lead to help-seeking.

‘Past frights’ (Hopton et al. 1996) can also undermine people’s confidence to assess and manage symptoms themselves. For example, Steven had called NHS 24 because his daughter had stopped eating and drinking. He and his wife Julie were particularly worried because their other daughter had previously been hospitalised due to dehydration and at that time they were told they should have sought help sooner.

Julie: *And you can say, ‘Och, it’s a cold and we’ll leave it’. And then when the weekend comes, you feel terrible when you have to phone a...*

Steven: *The out-of-hours*

Julie: *Aye, out o’ hours.*

ED: *Do you feel quite bad about calling them?*

Julie: *Oh aye, I dae. Mmmhmm. I try to hang on to the Monday.*

ED: *And why is that?*

Julie: *I just think when you see, you see thae many programmes and you see all thae hospitals and you see them on the computer you know, folk phone up for silly things and a waste of time.*

Steven: *You think sometimes it’s a cold she’s got and it’s a silly thing but, you forget it’s a child and it affects them more.*

Julie: *That’s right. That’s why we didnae phone that time wi Mia and the eh, a couple of year ago and they came, and they just rushed us straight in, I was mortified and he’s goin’ ‘She should have been in’ and I’m thinkin’ well I thought it was just a cauld. I get she was deterioratin’ a wee bit but I thought-cos kids can go doon the one minute and up the next like, it’s embarrassin’, you go to phone the doctor and they’re well doon and by the time you go to the doctor they’re runnin’ aboot like this!*

Julie’s comments here demonstrate the way in which media discourses about inappropriate use of health services and her own experiential knowledge of children’s health create competing imperatives; not to waste the time of health services and not to delay help-seeking. This highlights how these conflicting imperatives must be managed in decisions about help-seeking.

5.1.3 Calling ‘to be on the safe side’

A number of interviewees described calling NHS 24 in terms which suggested that the act of calling can be seen as a way of managing or mitigating uncertainty and risk. For example, Maggie said that she called ‘*to be on the safe side*’.

Maggie: *Ehm, but I thought just in case anything happened I should know what to look out for, so if the swelling got worse I didn’t know if that was an unusual thing or if it’s just because of the heat, ehm and unsuitable shoes. So it was just I was a bit uncertain, and I thought to be on the safe side I should seek advice in advance rather than, sit and panic all night and imagine that it was getting worse, than it might have been [laughs].*

Similarly John, who is a regular caller to NHS 24 as he calls every time he bleeds, says that he calls ‘*to be on the safe side*’ even when he knows the advice he is likely to be given.

ED: *Do you find the advice they give you, you can use yourself when you have similar symptoms or do you feel like you need to ring them kind of every time?*

John: *Well I usually ring them just to be on the safe side.*

ED: *Yeah.*

John: *Ehm, as I say to them I’m just phoning up for some advice, that’s all I want is just some advice and they give me the advice and I say ‘I don’t want a doctor’ I say ‘I’ve had this before so just, if I do this, this and this, will that help?’ ‘Oh yes’. ‘Fine’. And that’s it.*

The idea that calling is a way of mitigating risk was particularly present in the accounts of parents of young children. For example, Katie didn’t know what might be wrong with her baby who was upset and crying; she referred to calling NHS 24 as ‘*safeguarding*’ the baby as well as managing her own uncertainty.

Katie: *Ehm, I didn’t think it was anything too serious, but then I’ve never had a baby before so I don’t know, so, I’m like, is this the point where you should phone the- like it’s kinda knowing when to phone, and, I thought I’ll just phone NHS 24 because ehm, even if it’s eh, not serious at least it, like it’s safeguarding her if you know what I mean?*

Similarly Grant talked about calling NHS 24 in terms of being ‘*cautious*’ and dealing with the uncertainty of potential harm.

Grant: *Ehm, we were maybe slightly unsure initially of do we phone, do we not, eh, what do we do? And then we just, we kind of thought through ehm,*

ok, what's she done? She's hit her gum. There's blood coming out around her tooth. Ok, there's potentially, you know, potentially some damage there because, well, there's, there's bleeding. Ehm, so we thought right, ok, let's, let's just ehm, be cautious and, and call.

For many callers, and particularly for parents of young children, being cautious or calling to be on the safe side had to be balanced against concerns that they might be perceived as over-reacting to the situation.

Heather: *I probably, not that I worry but I would tend to think, 'What if I don't do something, and it's something?' I'd rather just do it. Even if it made me look a bit, you know, like an over-anxious mother, it's better to just check, just in case, cos you always hear people saying that, 'Follow your instincts', and, you know all that, so it's better doing it instead of regretting it, so, yeah.*

This concern about being seen as over-anxious or 'over-reactive' was raised in the focus group with mothers of young children and in many of the individual interviews with mothers (though not with fathers). It is a label that all of the mothers were familiar with, and almost all of them had at some point felt criticised for seeking help unnecessarily, though they claimed that it would not stop them from seeking help again if they were worried.

ED: *Do you, are you aware of that kind of, do people call you or call other people over-anxious mothers?*

Heather: *You do get a feelin', yeah, like at the doctors and things you can, sometimes in some situations with the kids, it's definitely something I'm aware of with other mums, and I don't want to be like that, but at the same time you want the best for your children, and you want to act at the best times, so I suppose you can judge and say yeah, there's over anxious mothers, but at the same time, you have to think about what's best for your own children, so if it does make you look like that at times, so be it. I think. Yeah.*

ED: *It is interesting, because people have said that to me previously that you know they're kind of aware of it, but it doesn't make, doesn't stop them.*

Heather: *Yeah, yeah, it wouldn't stop me callin', but on the phone I would be thinkin', 'Oh no, this woman's probably thinkin', or this guy, it's a nurse, they're probably thinkin' like, 'what they worryin' for?' But I would still call, yes, and be judged.*

Like Heather, most of the mothers said they feel that they know what is best for their children and that getting them looked after is more important than what other people

think. However, Heather's comment that she sees 'other mums' as over-anxious and doesn't want to be like them suggests that it is an undesirable label which people prefer to distance themselves from.

Some mothers recounted stories of times when they had persisted in seeking help for a child when told that there was nothing wrong, only to be proved right. These stories serve to reinforce the idea that following their instincts, even when criticised, is the right thing to do for their children, as illustrated by Holly's account when this subject came up in the focus group with mothers of young children.

ED: *Do you feel like people, sort of, suggest that mothers and especially younger mothers maybe are-*

Caroline: *Over-reacting. Aye.*

Karen and Holly [at once]: *Over-reacting. Mmmhmm.*

Caroline: *Definitely*

Karen: *I've had that on several occasions.*

ED: *How does that, kind of, affect you? Does it make you-*

Holly: *It annoys me.*

Karen: *It, it doesn't bother me because at the end of the day I would rather have my daughter checked out than, be on the safe side rather than sommat happenin' so, I'm, I'm just one of those people, people want to say anythin', just don't listen to them, I don't care.*

Holly: *No, see-*

Caroline: *It annoys me severely.*

Holly: *-it annoys me, especially ma, ma first child, I was only 19 when I had ma first child and I used to get it on regular basis. Ma wee girl at 18 months broke her arms, and I got the- they noticed in the x-ray the first, they only ever x-rayed her first, one ae her arms to begin with, and from that day I had her up 5 times, that week, cos I knew that somethin' wasn't right. They'd missed out the severe concussion in her head from when she'd fell. And, the fourth day I took her up and I thought look, there's somethin' not right with her arm. 'You're just over-reactin''. 'No, I'm not over-reactin' I was like 'you-, she can't do anything with that arm, she whimpers when you try to do anything with it', 'No, no you're-, this is just in your head'. 'Tell you what go and x-ray that and come back to me and tell me there's nothing wrong with it', and they had to come back to me and say 'No, we're sorry'. So it took for me 5 days of perseverin' to be told I'm over-reactin' for somethin' to get done. I think that's a bit-, I think just because you're young doesn't mean that you don't know what you're talkin' about, you know your child more than,*

better than anybody in this world knows your child, and if you know your child's not well then, who's the doctor tae argue with you?

However, even when being cautious, it is clear that mothers don't make the decision to seek help lightly and they may second-guess themselves or make apologies for seeking help because they have felt criticised in the past. For example, Tina told a story about a time when she had brought her then 3 year old son to the hospital after he hurt his arm falling off a bed. He had seemed fine at first, but when he started complaining she brought him to the hospital.

Tina: *Yeah a woman's intuition's, definitely... I've been proven, time and time again, people I know. As I say, took ma son to the, [hospital] and I, I apologised, I says 'I think I'm wastin' your time, I don't think there's anythin' wrong wi his arm' [...] and we came back to [the doctor] after havin' the x-ray he says 'You'll never believe this', because he had his arm up and down and round about and he says 'He's broke his arm'. And he went through to get a cast and [laughs] and he couldnae believe it either. Because it just goes to show that, you know, you may think 'I don't think there's anythin' wrong, I think I'm just bein' paranoid', cos I'm bein' told I was paranoid that much.*

ED: *Were you told that a lot?*

Tina: *Oh yeah, oh yeah it was 'fussy mother', proved every time that I was right.*

Tina's account here, of both following her 'intuition' and getting her son seen, while simultaneously apologising and dismissing her worries as 'paranoid' highlights again the difficulty of constructing oneself simultaneously as being a responsible user of health services and being a responsible parent who doesn't take risks with the health of a child.

At the same time, some parents had examples of occasions when they had felt criticised for failing to act quickly enough when a child was unwell, often because they had not considered the symptoms to be serious until the child's condition had deteriorated. This had happened to Claire during her most recent call to NHS 24.

Claire: *They, like I understand where they're comin' from, because they're at the other end of the phone and people are tellin' them 'Well my daughter has, or my child has-, she's swelled up and she's got a high temperature', but, they jumped to a lot of conclusions, soundin' like we needed to have her in to*

A&E straight away. And even when we rang on the Saturday, they were like, 'Why did you let her go to bed on Friday night when you know, when you didn't think she was too well?' Even though she was fine, you know, we really did think it was just, ehm, hay fever. And I suppose lookin' back now maybe we should have done somethin', but she didn't look, she looked fine, it was only the Saturday mornin', but they were sort of givin' out to us a wee bit!

This quote from Claire shows that even though she felt criticised by the staff member she spoke to and thinks that maybe she should have acted sooner, she also retains some confidence in her own assessment of her child's symptoms and feels that NHS 24 was perhaps overly risk-averse. She made sense of this by trying to see the situation from the nurse's perspective.

Claire: *Yeah. And I've no problem with that, with them givin' out, d'you know, cos fair enough, you know maybe we should of, ehm, but I think it's very hard for people on NHS 24 when they're at the other end of a phone to actually see the person and to get a full overall picture of what's happenin'.*

ED: *Yeah*

Claire: *Especially if the parents are stressed out or, they can't give you a clear picture of the situation. But, no I was, d'you know, it worked out alright in the end.*

Claire's acknowledgement here of the way that NHS 24 staff must also manage risks, in the absence of the visibility of the patient, leads her to accept their criticism of her decision. She seems to accept that staff, too, sometimes err on the safe side (Roberts 1992) and that they may be making decisions on the basis of less complete information than is available to the caller.

5.1.4 Awareness of and attitudes to risk

I asked many interviewees about their awareness of campaigns or information about illness in the media and how they thought it might affect them. Often people said initially that they weren't aware of such campaigns but, when prompted, some could recall having seen 'something' about hand washing, meningitis or stroke, reflecting the main focus of media campaigns in recent years. However, most people claimed that these campaigns don't affect them at all, which makes sense given that being seen as 'over-cautious' about symptoms or, worse, a 'hypochondriac' is undesirable. For example, Peter and Anna suggested that awareness-raising about meningitis

doesn't worry them and Peter retrospectively explained his decision to call NHS 24 about his daughter's earache as being solely due to his brother in law, whose anxiety he slightly ridicules by saying *'he kinda worries a lot'*.

ED: *Does that make you more worried though, that there is a lot of kind of, information out there about meningitis and stuff and so-*

Anna: *Not really, I don't I- personally, no, because... no...*

Peter: *Nah, I don't worry about things like that-*

Anna: *No, I don't really I, I-*

Peter: *If it's gonna happen, it's gonna happen, I mean it's-*

Anna: *Nah, personally.*

Peter: *No, obviously I mean we try and do what we can, in the house, things like that, to prevent things from happenin' but, yeah-*

ED: *But if he hadn't said to you it might be meningitis, do you think you would have still called or do you think you might have just said 'Oh it's an ear infection'?*

Peter: *No, I don't think I woulda done, ehm, unless, as I said earlier there that I kinda brought her home, just kinda sat her down, gave her some Calpol, and that was gonna be it. Ehm, he phoned outta the blue and says it could be meningitis, but Chris is kinda he's, for such a big strappin' lad he, he kinda worries a lot-*

Debbie and Euan expressed very similar attitudes to those of Peter and Anna when asked how they feel about being made aware of risks, especially risks to children. Again, they constructed themselves as unlike the sort of people who worry about these things.

Debbie: *And we're not that sorta folk that 'Oh there's a bug goin' about, you hae to mollycoddle them' and it's like if you get it you get it, you're gonna catch it. So we dinnae hide them fae it.*

Debbie and Euan described things like colds as a normal part of childhood and showed that they think it is unnecessary to shield children from such illnesses. However, they were careful to distinguish this from more serious illnesses, which they did feel a need to watch out for.

Debbie: *[...] so, naw we dinnae mollycoddle them, they want to go on out, they can go on out, they need tae get used to this kinda weather, we live in Scotland. They get a cauld, they get a cauld. If it's absolutely scorchin' oot*

there, go oot and enjoy it! But, there is other diseases and stuff out there that we do ken, that can be mare harmful-

Euan: *Aye, like mumps and rubella and aw that stuff-*

Debbie: *-so if there is rashes and stuff we do dae all the checks wi the glass and aw that so-*

Euan: *Oh god, aye. The glass.*

So, while they are very careful to portray themselves as unlike other, overly-cautious, parents, Debbie and Euan are aware of risks and check things like rashes carefully. They also told a story about taking their daughter to the paediatric A&E department with a rash (which turned out to be a soap powder allergy), showing that they are not dismissive of risks and are cautious about symptoms which they think might be serious.

In spite of claims that campaigns to raise awareness of risks don't affect them, risk discourses *were* present in many participants' accounts. This was illustrated through mention of things like meningitis, cancer, smoking and obesity. Most notable, as previously mentioned, was the idea that infancy is inherently risky. Some interviewees talked about the resurgence of childhood illnesses and presented explanatory accounts, often linked to ideas about germs and immunity. Both Nancy and Julie suggested that children are more likely to be ill now than in the past because '*things are too clean*' nowadays and children are not exposed to '*bugs*' or '*germs*' enough. Being exposed to bugs was seen by all of those who discussed it as a good thing. Doreen talked about a resurgence of TB which she linked to immigration and of whooping cough which she said was '*the mothers' faults*' for not getting children immunised following the MMR scare. The particular risks seen to be associated with medication were also present in many accounts and will be discussed further in chapter 6. People were predominantly concerned about drug interactions, though there were also some mentions of antimicrobial resistance and the idea that one can get too used to taking medications.

Ingrid had clearly thought about the impact of awareness-raising and spoke about it at length. She was highly critical of the emphasis placed on awareness of illness and

the imperative for individuals to be responsible health citizens and considered this to have led to increased demand for health services.

Ingrid: *Yeah, no I think probably, the medical profession have made a stick for their own back, or, maybe the newspapers have. There is far too much babble about illnesses, it's maybe the charities thing, but you're reading about this and that and the next illness and all this awareness raising I mean, you get rammed down your throat you must check for breast cancer every 10 minutes because something dreadful might have happened since you looked last, and, and people get this in under their skin you know, they, they're just looking out for problems all the time because you get drilled into you that you have to be aware and, and I think you could, you're generating a lot of hysterics, and, and a lot of extra work for people who have got quite plenty already, eh, does that make any sense at all? I mean, I think we just, we've just turned into a bunch of hysterics, you know, it's really sad.*

At the same time, Matthew and Ingrid were the only participants to mention environmental health risks such as those from air pollution and chemicals in food. They feel that these risks are more important than the individual risk of disease and that they are less frequently discussed. Even so, Ingrid describes them as worrying to 'some people', thereby distancing herself from the identity of the worrier.

Ingrid: *The things that do worry some people are the ones we don't hear anything official about, like eh, a lady who stays over the hill over there somewhere, she is very, very worried about the effects of eh, waves in the air, like eh-*

Matthew: *Mobile phone microwaves and that sort of thing-*

Ingrid: *This kind of thing, and she is convinced it is affecting her, and probably a lot of other people. And when you sort of talk to people, there's days when they're just not feeling right and, there's nothing really wrong with them but uugh they don't feel good, I just wonder if that one has got a point [...]*

Ingrid presented a sophisticated analysis of why certain risks are discussed and why others are rarely mentioned, including for economic and political reasons. She also highlighted social causes of ill health, stating that rising unemployment and crime rates mean that 'nobody's feeling safe and secure anymore, and that means your nerves get all shoogled up and, and that can make you ill as well'. I asked Ingrid and Matthew if they thought that awareness-raising might actually help people to look

after themselves better and, while they acknowledged the public health case for sharing information, Matthew maintained that it increases anxiety.

Matthew: *Obviously if it's something like a new Asian flu epidemic going around, you need to make people aware what the symptoms are so that they, well, don't spread it to start with and know what to do, but I think the sort of, when you hear on the radio oh this is national awareness week for some obscure illness, well yes ok, there are people who suffer from it, and you don't want them to be ignored, but at the same time, the general overall impression is that you've got to spend your life worrying about your health and [laughs] if you stop worrying about your health it'll look after itself much better-*

Of course while awareness-raising may cause anxiety for some people, others may find it reassuring. Paula mentioned that she had recently had a breast check and smear test and that she had also been sent a bowel screening test which she intended to take. She said that she found this level of screening reassuring, as she'd prefer to know if she is at risk and '*they always say if they catch it early you know it's much better*'. However, having explained clearly why she thinks screening is reassuring, Paula went on to describe having experienced considerable anxiety in reaction to risk information about diet.

Paula: *No, it hasn't, you know I think that the breast screening thing's been around for a long time hasn't it and you just kind of think well, it's best to be like that. The thing that I don't like particularly is ehm, when they, on the rare times I've watched TV is, when they talk about heart attacks and stuff like that, and what you shouldn't eat, because I feel like that's a bit OTT, you know the general person, they're ok to have a packet of crisps now- you know, [...] That's the thing that I don't like, I just think they bombard you with that, and that does make you think, heart attack, you know, you don't really want to know that I don't think. Well, cos I, when I was having my panic attacks, and I did go to the doctor, and I said [laughs] said, 'I had some chips in the chippy the other day', she laughed at me and she said 'You eat such a healthy diet', she said, 'when they put programmes on like that' she said 'they're talking about people who have them every single night of the week' [laughs] so, I was like 'Oh, ok then'. She said 'One time going to the chippy I think you'll be ok!' And then I decided that I probably wouldn't watch those kinda things, on television, you know, so. I think there's a good and a bad side of it, but that kind of thing [screening] I find quite reassuring.*

Overall, it was clear that while most interviewees claimed not to be worried by awareness-raising or media scare-stories, many of their accounts are shaped to some

extent by risk discourses. It is possible that in some cases these discourses are also shaping how people interpret and respond to symptoms.

5.1.5 Professional and organisational risk-aversion

As discussed in chapter 4, some of the staff I spoke to consider that NHS 24 is a risk-averse organisation and that, as a result, patients are sometimes seen unnecessarily, thus raising expectations that people will regularly be given face-to-face appointments. There is, therefore, a cycle in which the risk-averse behaviour of staff is both a response to, and generates, the expectations of callers. Many staff saw this as problematic but felt that it was also unavoidable, as illustrated by the following exchange from one of the staff focus groups:

Simon [nurse- staff FG2]: *The problem, the problem wi telephone triage is that, you have to err on the side of caution, there is a lower threshold for gettin' someone seen, there's no question about that. If I lined up all the people that I sent to the PCEC and actually saw them face-to-face, you wouldn't, you probably wouldn't get half of them seen-*

Sara [nurse]: *You'd just be at half of them!*

Joanne [call handler]: *That's the difficulty-*

Simon: *-but, and obviously, and obviously in NHS 24 everything you say is being recorded, everythin's bein' digitally recorded, everythin' you say-*

Annabel [nurse]: *It's under scrutiny!*

Simon: *-every nuance of your voice, every, every attitude you've got or anything's bein' recorded. So ultimately, you know, there is that lower threshold for gettin' people seen.*

Sara: *And also we have to go with what they say.*

Annabel: *Absolutely, mmmhmm.*

Simon: *Yeah, mmmhmm*

Sara: *We have no choice. Even if you strongly suspect they're tellin' us porky pies. We can't see them.*

Annabel: *But if you repeat it and you say 'So you're telling me this' and they're sayin' 'Yep', and you think to yourself, 'this is nonsense', you can't sit there and say 'Well actually I think you're lying so I'm not going to get you seen'-*

Simon: *That's right, yeah*

Annabel: *-cos that'd be your registration gone, in a, in a one off. So you're right you would, end, err on the side of caution because you can't actually call the patients liars.*

This exchange shows the difficulties for staff in establishing not only the nature of a patient's symptoms but also the legitimacy of their claims to care without being able to see them face-to-face. They link risk assessment not just to the potential dangers faced by the patient, but also to the dangers they themselves face if they make a mistake. In safeguarding against both, they are forced to give up some of their control over what they determine to be legitimate use of the service. Their awareness of risk to themselves is heightened by the fact that they are being recorded.

One interviewee, Angela, who is also a health visitor, suggested that people are encouraged by nurses and health visitors to see their GP if they have any doubts about symptoms.

Angela: *[...] -there's nothing to be done for your child apart from painkillers, so ehm, so yeah, but obviously, err on the side of caution, that's often- and we tell mums that all the time, err on the side of caution, especially with the babies, ehm please don't hesitate to come and see- [laughs] the health visitors say that all the time 'Please don't hesitate to come in and see the GP, anything at all!'*

Like the nurses, Angela linked the message to 'err on the side of caution' to a need for health visitors to protect their professional registration, but she acknowledged that this is likely to encourage increased use of health services.

Although the concept of the 'risk society' underpins previous studies on NHS Direct (Goode et al. 2004a; Hanlon et al. 2005) and O'Cathain et al. (2007) have explored the attitudes of NHS 24 nurses to risk, less is known about the ways in which organisational risk-aversion may be perceived by callers. Many of the interviewees in this study felt that NHS 24, and health services in general, can be overly risk-averse. This was seen by some older people in particular as being a 'modern' social trend and it was given as an explanation by a number of people for what they described as some of the more frustrating aspects of using NHS 24, such as the repetition of questions.

Matthew: *I think what pervades a lot of society now is lack of trust which is brought about by the fact that solicitors nowadays if somebody comes in and says 'I've got a complaint', 'Oh, we'll sue', when in the old days it's 'Hmm, not much of a complaint, go away'. [laughs] [...] And I suppose this is the background to why there's all this, you know, having to repeat details all the time, having to make notes, carefully cover them-*

As illustrated by Claire's comments in section 5.1.3, some people's reactions to risk-aversion indicated that they have come to accept it as the norm and some interviewees were able to rationalise what they saw as an overly cautious reaction to symptoms. For example, Josie was surprised that NHS 24 wanted to send an ambulance for her, yet at the same time she has developed an account which explains why 'they were right'.

Josie: *I don't think they expected to want to send an ambulance, that I didn't expect. But it were the fact that, it were startin' to affect, it weren't affectin' me breathin', but me throat were tightenin', as it does sometimes with an allergic reaction. So, ehm, I think they were usin' that... yeah, they were right, it were a precaution, cos they didn't know whether me throat were gonna close, I were gonna stop breathin' or anythin' like that. I didn't, I didn't expect them to want to send an ambulance out, ehm, when Joyce were talkin' to them about me throat closin' and she said 'Mum, they want you to go down', 'Right ok we'll do that', ehm... you know but the thing wi the ambulance no I didn't expect that.*

Josie still refused to go to the hospital in an ambulance and was taken there by one of her children, but her account here shows that she thinks the NHS 24 nurse made a decision on the basis that her symptoms *could* be serious and *could* develop into something worse; the same reasoning which led many interviewees to call NHS 24. This echoes the point made by Roberts (1992) that uncertainty and the need to both assess and mitigate risks is an area of common ground between professionals and lay people. However, Josie's account also suggests that organisational risk-aversion may put people off calling NHS 24 if they feel that the response will be disproportionate and that they may use up resources which they don't think they really need; something that was certainly felt by Andrea.

Andrea: *[...] even when Cameron had croup, ehm, the night that they came to lift Cameron in the ambulance, I says, 'Look, it's fine, I'll get him to the hospital just tell them, tell them I'm on my way', sorta thing, and she was like, 'No, no, we can't take that chance'. Ehm, she says, 'It's, it's on its way,*

it'll be with you'. And I'm like- I feel sometimes, although it was his breathing and he was trying to catch his breath for coughing, I thought, right, I can get him to the hospital. I know he'll be fine, sort of thing but, ehm, I think sometimes there's, there's other more important things and dinnae want to feel that I'm wasting their time sorta thing

On the other hand, professional or organisational caution may be experienced by some callers as welcome and indeed reassuring.

Grant: *And then in terms of the, the conversation that, that we had with the, the nurse adviser and the, the way that they... the way that they, if you like, the way they assessed-*

Jodie: *The way they, yeah, they handled it.*

Grant: *-assessed our, our daughter over the phone, asking us questions, asking us to look for things-*

Jodie: *Was very, very thorough.*

Grant: *-was very thorough.*

Jodie: *Very thorough.*

Grant: *And...*

Jodie: *And very cautious.*

The link between thoroughness and cautiousness made here by Jodie and Grant shows how the depth of questioning and the length of time the nurse spent ruling out any serious injury to their daughter was appreciated and led to satisfaction with the call. The ways in which calls to NHS 24 may be experienced as reassuring, or not, will be further explored in the next section.

5.2 Reassurance

The importance of reassurance has been highlighted in relation to parents seeking advice about children's illness (Cunningham-Burley 1990; Cunningham-Burley and Maclean 1991; Neill 2000) and in relation to consultations about conditions such as arthritis (Donovan and Blake 2000) and cancer (Stark et al. 2004). Significantly, Donovan and Blake (2000) note that clinicians' statements which are intended to be reassuring may not always be interpreted as such by patients, particularly if they feel that their worries have not been acknowledged. Therefore, it is necessary to understand what it is that *does* reassure people in their interactions with health services. In this section, I explore the importance of reassurance to the callers I

interviewed and the ways in which they experienced their calls to NHS 24 as reassuring, or not.

5.2.1 Calling NHS 24 for reassurance

Reassurance was highlighted by many of the interviewees in this sample as significant in their interactions with health professionals. Encounters with friendly and reassuring health care workers had made a lasting impression on some interviewees and being made to feel reassured featured in accounts of satisfactory health care interactions generally. Paula emphasised how important she thinks reassurance is, particularly as part of the role of the nurse, although she felt this was being lost as nursing becomes more professionalised.

Paula: *I think a big thing, I suppose cos I'm a counsellor anyway but a big thing is reassurance. I think that's huge, you know if you're not being reassured, one thing I will say is that I think that, cos I worked for Marie Curie for a while, and that, and I would say that nurses in my day used to be nurses, real nurses, in the caring of the, talking to patient type and just sitting with them, that kind of thing, and, auxiliaries were different, and now the auxiliaries are the nurses, and the nurses are like mini doctors. Ehm, and I'm not sure that that's a good thing or not really. I think that the care, cos I think that people need a lot more reassurance, when you're reassured, cos even at the end of the day if you're reassured and, you shouldn't be, well you know, you need that, you need somebody to say you know 'You're alright, it's ok, and we're gonna give you this and we're gonna, you know, to put you on a, you know, a level, to make sure you're alright'.*

When I asked people about their understandings of the purpose of NHS 24, a number of interviewees mentioned that they think it is there to give 'support and reassurance', or 'advice and reassurance'. Seeking and being given reassurance was a prominent theme in many accounts of calling the service. One third of interviewees gave 'looking for reassurance' as one of the main reasons that they called NHS 24. For example, Katie said that she just wanted someone to tell her that her baby was ok and Tomasz said he was hoping that he would be told to stay calm and to see how his baby was in the morning. Grant wanted reassurance 'if it could be given' that his baby's bleeding was not unusual after an injury and Gail also wanted reassurance that her symptoms were normal. Both Laura and Paula gave 'a bit of reassurance' as

their first answer when asked what they were expecting when they called, as did Natalie.

ED: *And, so when you phoned, what were you expecting from them?*

Natalie: *Ehm... To be honest I was looking for reassurance [laughs]. Ehm, that it was going to be ok, and that this is a normal symptom, and that it will go away [laughs]. Ehm, and I probably would have worried about it otherwise.*

The idea that people would have worried had they not called NHS 24 was a recurring one, as previously mentioned. A number of interviewees described feeling ‘worried’, ‘frightened’ or ‘panicked’ before they called and thought that their anxiety would only have increased had they not called NHS 24.

Paula: *Ehm, so and I think that, ehm, my impression of it, or what I would, what I like about it is that I think that... we need something like that, because I think that to get on the phone and be able to talk to somebody actually can be really reassuring, whereas if you don't and then you go on and on and on, you could work yourself into a bit of a stew for no reason really, cos you're actually talkin' to somebody, but not always do you need to see somebody. You know cos you, there would, actually to have gone to the doctors, well we can't see anything, so you know you might as well ring somebody that can answer you and you know, ask you the right questions.*

Interestingly, some of those who were uneasy about whether or not their calls had been a legitimate use of NHS 24 referred to the fact that they had been reassured in order to construct their call as appropriate. For example, I asked Maggie if she thought that her call to NHS 24 had been an appropriate one:

Maggie: *[Pause] Ahm... [long pause]. Now when I was speaking to them I did keep going 'I'm really sorry, I feel like I'm wasting your time' but that's the sort of thing that you say. Ahm, genuinely... it probably wasn't entirely, if I had left it say 3 or 4 hours, til later in the night, the swelling would have gone down and the painkillers would have kicked in, ehm, and it probably... I probably would have thought 'och it's ok'. So if I'd waited 3 or 4 hours, I think perhaps I might not have phoned. So in that sense perhaps I phoned too early. Ehm, but in terms of it gave me peace of mind, and I was able to just you know- I knew then that I was doing the right thing, so there was nothing I should be, ehm nothing else I should be doing and I also knew what to look out for in case it did get worse, ehm, personally I found the reassurance very useful so in that sense it was appropriate. Ehm, but there is always a kinda nagging thing you don't like to bother-*

Similarly, Gail thought that while she may have been wasting someone's time, this might be justified given that she was reassured by her call.

Gail: *I probably shouldnae have phoned, to be honest, I was probably wastin' somebody's time, but-*

ED: *Do you think that?*

Gail: *Well I... I don't know... I suppose if I was put at peace then no, but they could have been on the phone helping somebody who really needed their help. D'you know what I mean?*

Both Maggie and Gail are aware that they could be seen as time-wasters, and they show the required level of concern about this to establish that they are responsible health consumers, but at the same time they use the importance of reassurance to construct their calls as legitimate. This echoes the finding from Adamson et al.'s (2009: e230) study that 'feeling worried was generally sufficient justification for consultation in response to any symptom'.

When talking about other people's use of NHS 24, reassurance was again mentioned repeatedly. Tina said that she thinks her son and daughter-in-law call NHS 24 for reassurance as their baby has had a lot of health problems and Jim also thinks that his daughter calls for reassurance about her baby, who has a heart problem.

Jim: *Ehm, and, I think, my daughter's used them for the baby. Just for a bit of advice during the night. And, I think, that's useful. Ehm, even that. Just to reassure you everything's ok and this is what to do. Just to have them there for that's excellent. And it makes all the difference.*

Irene thinks that her partner called NHS 24 about her illness because he wanted reassurance for himself. Similarly, Julie, whose father has started to go to his GP and to call NHS 24 a lot since her mother died, thinks that older people living alone need a lot of reassurance.

Julie: *See that's what I think they're on their ane and just panic and, I mean ma dad's like that noo, ma dad used to say to ma mum, 'For god's sake, I cannae go oot anywhere and I get the bloody ambulance at the door', see now, that mum's not there, he's startin' to go down that route and I thought well 'Don't you dare go down that route dad!'.*

Steven: *Aye, he's always at the doctor.*

Julie: *Aye, and he'll say to me, I mean he's 76, and he's overweight, never off the go like, you know he's a big, big man, but eh, 'I need to go to the doctor and that'. 'Whit for?', 'To see about ma legs' and I'll just tell you dad, lose 5 stane o weight, I can tell you that the noo. And eh, 'Aye right enough, that's what they telt me'. And it's the reassurance I think, I think it's mebbe the reassurance bit like.*

It is interesting here that Julie links her father's increased use of health services to loneliness and lack of confidence following the loss of her mother. This suggests that both the GP and NHS 24 are understood as fulfilling a social support role; perhaps because these problems have become medicalised but also perhaps in the absence of alternative support.

Regardless of whether or not they had called for reassurance or gone into their call expecting to be reassured, for many of the interviewees in this sample it seemed that their most recent call to NHS 24 *was* reassuring. This was important to people given how anxious many had felt before calling, as described by Tina.

Tina: *In ma mental state, yeah, I needed that reassurance, I really did need it. Ehm, even though I wanted it instantly, at the time but... you know I had to be patient and wait because there are other people sick as well, you know you've gottae realise that, you know. There's other people need, that are worse off than you are! So.*

For some interviewees, just talking to someone was reassuring and many mentioned that they found the attitude of NHS 24 staff to be reassuring. Claire thinks that the staff '*seem to be very pleasant*' and seem to '*want to talk*', which makes her feel comfortable about calling. Laura said that she was reassured because the nurse that she spoke to was '*lovely*', while Paula said that she felt listened to and taken seriously and that the nurse she spoke to was '*really nice and very reassuring*'. Katie thought the nurse she spoke to was very calm and Lauren thought everyone she spoke to was '*really nice*'. The importance of the staff's attitude in making people feel reassured when they are worried is illustrated by Grant:

Grant: *And I would say that the nurse adviser was also just, she was extremely reassuring and calm. Ehm, she was... she was lovely, she was really, really, I suppose just the sort of person that we needed to speak to at that, that point in time, where we were both quite, quite concerned, a wee bit shaken up, ehm...*

A small number of interviewees didn't explicitly mention reassurance but talked about their calls in terms which suggested that they had been worried and were given advice which alleviated their worries. However, it is worth mentioning briefly the 4 participants who didn't discuss reassurance and whose accounts *didn't* suggest that they felt reassured. These were all adults who called for themselves and who felt that their symptoms were particularly severe. James and Robert were both dissatisfied with the advice they had been given when they called, as they were still in pain, and both went to a hospital to be seen the next day. These men were clearly not seeking reassurance; they were seeking relief from their symptoms and were determined to get it. Grace and Andy described themselves as satisfied with the self-care advice they were given, but both called NHS 24 again the next day. Grace was told to contact her GP and Andy was sent to a primary care emergency centre. In these cases the callers' pain and distress meant that they could not be easily reassured.

The way they were spoken to by staff had significance for callers both in terms of their satisfaction with the call but importantly also in terms of how reassured they felt. Nobody in this study expressed any complaints about the staff, although, as noted in chapter 3, people are unlikely to have been asked to participate in the research if they seemed unhappy with the outcome of their call and are more likely to have been asked if the adviser they spoke to felt they had established a rapport. However, it was not just interpersonal communication that was reassuring; the structure and content of the call was also significant.

5.2.2 Call structure and questioning

It has been noted in other studies of helpline use that interactional difficulties can arise when a caller and call-taker are pursuing conflicting goals, with the caller wanting immediate advice and the call-taker needing to collect detailed and specific information which may not seem relevant to the caller (Firth et al. 2005).

Anecdotally, I have been told that the repetition of questions and the length of time it takes to get through an assessment can be frustrating and puts people off using NHS 24. Indeed, some of the interviewees in this study told me that they have been put off

calling NHS 24 in the past because they felt they would be asked too many questions or questions which they felt were irrelevant and presented a barrier to getting help.

Andrea: *I'm just looking for help basically as quickly as possible and when you do phone NHS 24, I know like you could speak to 4 different people and each time they go through the same things, your name, your date of birth, your telephone number, how you're feeling, your symptoms and you just feel like saying, 'Please, just somebody make me an appointment cos I feel really rubbish and I just want to be seen'. Ehm, but I know there, there's different sections and they're basically doing their job, ehm, but sometimes I think it's kind of prolonging it rather than, ehm, getting you through to see the correct person quicker.*

However, an interesting finding in this study is that a number of interviewees described feeling reassured by being asked lots of questions, particularly if they thought that they were 'sensible' questions or 'the right questions'.

ED: *So how did you feel about the advice you were given when you rang NHS 24 then, was it useful?*

Katie: *Ehm, it was very good, ehm, the guy was very calm and he just asked me all the questions, and ehm, just asked me really sensible questions ehm to find out what was wrong, and he asked me what I'd tried and stuff*

This made people feel that they were being listened to and taken seriously and that a thorough assessment was being done, as described by Paula:

Paula: *Yes, I felt I was listened to and I did feel that he was very good with me, he was very thorough, the fact that he asked the, you know, I'm not going to say the proper questions, but he asked the questions that I felt was what I needed to be asked, ehm so that he could get, and I felt that he dealt with it, ehm, in a good way, and he did reassure me and he also said if it does get worse or you have this or that then ring us back, ehm so he wasn't, he didn't pooh-hoo it, he didn't, you know he was taking me seriously, he was saying if there is blood in any of it get back on to us, and you know he wasn't ehm, he was taking it seriously and I felt that he really listened and he told us what to do. And then he said 'and ring the doctor in the morning if it's still persistent, you know and it's still quite as strong', which is what we did, ahm cos it was.*

NHS 24 calls are organised in such a way that serious or urgent conditions are ruled out before a final disposition is given. This means that people will be asked a series of questions designed to ensure that nothing significant is being missed. Previous research has identified that this type of questioning can be experienced as

unnecessary and even disturbing (Egbunike et al. 2010). However, for some participants in the present study, it seems that the inclusion of such questions served to reinforce the idea that there *could* have been something serious wrong, while the nurse or call handler's reaction to their answers simultaneously reassured them that there *wasn't* anything serious wrong and so this questioning was experienced as reassuring.

Peter: *[...] they just asked sort of general questions cos I think it can have, ehm, you know it can be a sign of sort of more serious illnesses, so they asked us things, I can't remember exactly what it was but is she off her food is she, ehm, sort of got a temperature that sort of thing. Ehm, and as I say I answered all the questions, they obviously weren't concerned that it was somethin' more serious*

Maggie: *[...] and you know I explained that it wasn't an emergency and I didn't feel dizzy and, she asked all these questions, to obviously address the fact that it wasn't an emergency, I was just lookin' for advice.*

Ingrid: *And we got eh, you know asked a whole load of questions and eh, they sounded as if we could start breathing normally because it was-*

Matthew: *It was obvious from the questions, they had something in the back of their mind that it might be, but they cleared that off, then they said well ok we'll get a medic to ring you in 3 hours' time or something-*

The specific questions that were asked and even the ordering of the questions took on particular significance for some callers, perhaps because it gave some insight into the process of assessment and gave them more of an understanding of where risks are likely to lie, thus increasing their own knowledge and capacity to assess symptoms.

Tomasz: *You know, I spent whatever 5 or 7 minutes on the phone, they asked, well, just by, by listening to the questions, you know the priorities, what they were looking for, what kind of information are you looking for, you know, I understood that you know the high temperature is not the worst thing which might happen, as long as the breathing is fine, pretty much everything else can- is ok.*

ED: *Yeah, so did you feel like you learned something from the call?*

Tomasz: *Yeah definitely. Yeah. Just the order of asking questions, you know, the, where the particular questions are positioned, you could easily judge what was crucial and what wasn't.*

For some parents, the process of participating in the examination of their child also reassured them that a thorough assessment had been done.

Heather: *Yeah, I was ok with it, they reassured me, and it obviously wasn't, well they actually made me get him out of bed too, it was quite late but I know it's for his own health, so I had to get him out and do all the things they said, ehm, so by doing, actually speaking to them as I was examining him, by how they were instructing me, like that was enough for me, ehm that was as good as a doctor kinda looking at him, for me, or someone lookin' at him, so I was really, I was fine with that, that was quite good.*

This was also the case for Grant and Jodie; while the assessment of their daughter introduced the possibility of a risk they hadn't even considered, it then ruled it out and also gave them new knowledge which they found reassuring.

ED: *So how did you feel at the end of the call about what you'd been told?*

Grant: *Ehm, I would definitely say, well, reassured certainly. Ehm, glad that we'd phoned up. Ehm, again, because of the reassurance that we'd been given and I suppose the reassure- part of that reassurance came from the, the instruction we'd been given to, to check our daughter for, for, you know, for skull fractures. Ehm, 'cos it's not, it's not the first thing you think of, or it certainly wasn't the first thing, it wasn't even the fifteenth thing that [laugh] my wife and I thought of after it happened, was 'oh aye, the chances are she's hit her head so she may have fractured her skull', that never really crossed our minds. Ehm, but once the, the nurse adviser had taken us through it we did see the sense in it, we thought oh right, ok yeah, fair enough. That never occurred to us. But, one, we've, we've checked ehm, and we've reassured ourselves and the nurse adviser that there are no signs of it. And we now know what to look out for over the next say 12 hours or so. Ehm, if there's anything like, anything like the, the signs that we were told to look for pop up then, then we know there's, we know at that point that there's reason to be concerned and there's you know, we've got, well, we need to phone treble 9 immediately. Ehm, so really, yeah, we were given the reassurance that it... gave us both, my wife and I both relief. Ehm, to know that although our daughter hadn't been seen face-to-face, we were both comfortable and confident that she'd been given a, kinda a thorough consultation if you like. And, or she'd been assessed thoroughly, ehm. So yeah, we were much more, much more relaxed [laughs].*

One aspect of calling NHS 24 which was experienced as increasing, rather than alleviating, anxiety was waiting for a call-back, especially for people who were already feeling quite worried when they called. For example, Tina had been told that she might have to wait 2 or 3 hours for a call-back and described being 'in a panic'

and attempting to seek help from other sources, such as her local pharmacy, while she waited. Similarly, Claire found waiting for a call-back to be the least satisfying aspect of the process, and had made a repeat call while waiting.

ED: *And were there any ways that you feel from your experience of NHS 24 that it could be improved?*

Claire: *[Pause] Ehm, the only thing I wou- well, it's very hard though. The only thing would be if it was, obviously if it was an emergency, we'd probably bring them into A&E, and I understand that they're very busy, but, from the moment of the first call, and then they say they'll call you back, it can be anythin' up to 3 hours. And in that 3 hour period a lot could happen. Ehm, whether they can reduce that time I don't know [...] Cos I know on the Saturday mornin', no on the Sunday mornin' when Sinead's temperature was really, really high, it took them ages to call back, and we ended up callin' them again.*

O'Cathain et al. (2005) have suggested that lengthy waits for a call-back can create a loss of trust in the service and Richards et al. (2007) have described how anxiety may be increased when people don't understand how calls are prioritised. However, to some extent, the initial assessment by the call handler may mitigate the distress caused by waiting for a call-back if it is experienced as reassuring and the caller understands that the reason for the wait is that their symptoms are not considered to be dangerous.

Matthew: *I mean a lot depends upon your reactions. I mean we could have said 'Oh, it was terrible to wait for 3 hours', but then, they made, having made it clear that they realised it wasn't anything life-threatening, they said we'll get a nurse, and the chap who came on was extremely helpful, and kindly.*

A very small number of people did express concerns about the adequacy of telephone assessment, with Robert, Claire and Josie all suggesting that NHS 24 nurses being unable to see the patient might be a barrier to accurate assessment. However, most callers seemed satisfied that they, or the person they were calling about, had been thoroughly assessed and they experienced this as reassuring. A particular feature of the call that enhanced this reassurance was the worsening statement.

5.2.3 The ‘worsening statement’ as reassuring

The ‘worsening statement’ is a term used by NHS 24 to describe the advice given to callers about what they should do if the patient’s condition changes or gets worse. It involves the nurse or pharmacist reiterating what they have been told by the caller and what advice they have given. This makes clear the information on which they have based their advice and serves to reinforce awareness that the advice given should be followed for only as long as the symptoms remain as described. The adviser then describes any signs which might indicate that the patient’s condition is deteriorating and what to do if that should happen. This ‘just-in-case’ advice (Landqvist 2005) may be for additional self-care, to call 999, to go straight to A&E or to call NHS 24 again. The inclusion of the worsening statement serves a number of functions, including confirming that the caller has understood the advice, but it is also an important way for both the individual staff member and the organisation to mitigate possible liability issues (Firth et al. 2005).

Interestingly, the worsening statement is one of the key things that callers seem to remember about their call to NHS 24, as it was mentioned by most of the interviewees. When I asked people about what advice they had been given, they almost always mentioned that they had been told to call back or to call their GP if they were still worried or if anything got worse. Even Alison, who told me a number of times during her interview that she has a poor memory and had difficulty recalling the circumstances of her call to NHS 24, remembered that she had been told that she could call back if she needed to.

ED: *What did they suggest to do?*

Alison: *Ehm, tell you the truth I cannae remember. It’s about over a month ago, I’ve got a terrible memory.*

ED: *Ah, no worries, that’s ok.*

Alison: *I’ve got a terrible memory.*

ED: *Ok.*

Alison: *They told me, they told me if I was still, I could phone them back but-*

Karen [Alison’s daughter]: *Did they no say take paracetamol?*

Alison: *I cannae remember Karen it was that long ago, about a month.*

Karen: *I'm sure they teld you to take paracetamol.*

Alison: *Mmm. Cannae remember it was that long ago but they told me if I was thingy I was to phone them back, which I never did.*

Claire recalled being told to call back if there was any change in her daughter's behaviour and Katie felt reassured because the nurse she spoke to suggested some ways to try to calm her baby but said '*if that doesn't work and she's still upset phone back*'. Tomasz remembered being told that if anything changed he should call back and Irene was told if her symptoms got worse she should '*just phone again*'. Jim mentioned at least 3 times during the course of his interview that he had been told he could call back.

ED: *What was the advice that they gave you? What did they suggest?*

Jim: *They, to, ehm, to take the tablets and to, and, you know, they're very good because they said, you know, anything else just phone back, don't, don't be afraid to phone back again and even that, you know, it was very good, I felt. You know, it means that you know you've got some, sort of, support there.*

[...]

ED: *And did you feel there was any way in which the experience could have been improved for you?*

Jim: *Ehm... No. I was quite pleased with it. I thought everything was good. And one of the things that I mentioned earlier was that they also mentioned, you know, call back if you're not confident or you're still bad. I mean... I don't think there's much more they could do but at least you had somebody to talk to if you wanted to.*

[...]

Jim: *And for somebody to say, 'Look, don't be frightened to phone right back if, you know, if that doesn't work or if you want to try something else or'... Yeah, it was very good, yeah.*

What is particularly interesting is that many of the callers in this sample seemed to interpret the worsening statement as affirmation that they had 'done the right thing' by calling and some also seemed to take it as almost an encouragement to call again. It is, therefore, possible that the worsening statement may have the unintended consequence of encouraging increased service use. For example, Steven recalled being told not to worry about repeatedly calling.

Steven: *It- what they did, and what I got was fine, there was no improvements that could have been made, the lady on the phone was fine, she phoned back within the hour that she said they would do, ehm, nothin' was too much trouble for her. She asked as many questions as she needed to and I answered them the best I could. And she said if you're not happy with, within a couple of hours phone us back again, don't worry about keep phoning us.*

Of course, it is not possible to confirm if this is exactly what the nurse actually said, but the impression that Steven was left with here is significant. Similarly, Heather recalled being told that she should '*feel free to call back*'.

Heather: *Ehm, they kinda thought it was nappy rash at first, but because it was swollen, they ruled that out, they didn't actually say what it could be, they just said keep an eye on it, check it tomorrow, if it becomes uncomfortable, ehm, go and see the pharmacist, or call back, feel free to call back.*

Some people did re-contact NHS 24 or called their GP because their symptoms hadn't improved. About 5 people told me that they had called NHS 24 again the next day, and the same number said that they had contacted their GP the next day. In such cases, it is possible that the initial call to NHS 24 legitimised further help-seeking (O'Cathain et al. 2005).

5.3 Summary

The worry that symptoms might be or become serious has been identified as a trigger to consultation in previous studies of illness behaviour (Roberts 1992; Hopton et al. 1996; Kai 1996; Neill 2000; Hugenholtz et al. 2009; Leydon et al. 2009). In this chapter, I have characterised this worry and uncertainty as a sense of risk. Although the literature on risk generally speaks to global uncertainties, the concept of the risk society is also useful in understanding the social and cultural context in which people make decisions about dealing with acute symptoms (Hugenholtz et al. 2009). I have noted that risk discourses shaped many participants' accounts of how they interpreted and responded to symptoms, even though they did not generally use this term themselves.

People often don't feel competent to assess the potential danger of ambiguous symptoms and feel a need to seek expert knowledge (as will be discussed further in

chapter 7), sometimes just ‘to be on the safe side’. Calling NHS 24 is presented here as a way of managing and mitigating risk and sharing or passing on the burden of, and responsibility for, risk assessment. This is not done lightly, however, as the label of ‘over-anxious’ or ‘hypochondriac’ is a highly undesirable one, indicating the morally charged nature of health related decisions. The risk of being labelled as irresponsible for seeking help too quickly or for waiting too long must also be negotiated in decisions about calling (Goode et al. 2004a).

NHS 24 staff must also strike a balance between avoiding risks to themselves and to patients while not encouraging unnecessary use of health services. The risk-averse policies of the organisation and the algorithms used by staff are designed to assist with the former; however, it is interesting that they may be counterproductive in terms of the latter. These very policies, such as detailed questioning about the presence of life-threatening symptoms and the provision of a ‘worsening statement’, seem in some cases to reassure callers that they were right to be worried about the potential for serious illness and that they have done the right thing in seeking help. This, combined with the friendly manner and careful listening of staff, has the potential to be experienced as legitimising help-seeking (O’Cathain et al. 2005).

The reassurance provided by calling NHS 24 therefore plays a part in enabling people to deal with uncertainty and to manage their symptoms. Reassurance was constructed by a number of participants in this study as both an appropriate reason for seeking help and an appropriate call outcome. For some, the very fact that they were reassured mitigates their fears that they may have been wasting somebody’s time, echoing the findings of Adamson et al. (2009). Reassurance has also been linked to satisfaction in calls to NHS Direct (O’Cathain et al. 2000) where the most common reason for satisfaction with the advice given was that it was reassuring. This chapter has demonstrated how calling NHS 24 can be experienced as reassuring as well as highlighting how some aspects of service provision, such as the use of call-back, may conversely increase anxiety.

6. Self-care, help-seeking and responsibility

The aim of this chapter is to situate interviewees' decisions to call NHS 24 in the context of their attitudes to health, illness and help-seeking more generally. I explore some of the ideas about self-care which were expressed in the interviews, with a focus on attitudes to self-medication and medicating children. I outline the extent to which people reported having taken measures to try to care for themselves or their children before their most recent call to NHS 24. I also explore the range of attitudes to seeking help that were expressed in the interviews, focussing on attitudes to waiting and the impact of access to primary care on people's help-seeking decisions.

I then discuss what participants' accounts reveal about their understandings of 'responsibility'. As discussed in chapter 2, moral discourses around health and help-seeking mean that it is important for people to be, and to construct themselves as, responsible users of health services as opposed to 'time-wasters', but I suggest that there are two orientations to responsibility apparent in these accounts. On the one hand, people expressed clear ideas about what it means to be a responsible 'health consumer' (Goode et al. 2004a), drawing on moral discourses about appropriate behaviour and not wasting the time of health providers. With regard to this meaning of responsibility, it is seen as important not to call NHS 24 unnecessarily; however, calling NHS 24 may be a way of avoiding unnecessary use of other services (O'Cathain et al. 2005). On the other hand, there were accounts which demonstrated the way in which seeking help or advice was clearly understood as taking responsible action, echoing the findings of Pill and Stott (1982) who demonstrated that not seeking help or delaying for too long could lead to accusations of irresponsibility. Therefore, while calling NHS 24 can be understood as abdicating or sharing the responsibility for dealing with symptoms, it can also be seen as *taking* responsibility.

This makes for a complicated picture when seeking to understand what is meant by appropriate use of NHS 24 and the findings presented in chapters 4 and 5 provide important context here. If NHS 24 is understood as 'somebody you can call' for advice, then calling for reassurance about even the most minor symptom can be constructed as appropriate and responsible as it will allay fears and avoid potential

use of other services. However, if NHS 24 is understood as an emergency service, then calling about minor symptoms could be labelled as irresponsible and wasting time.

6.1 Health, illness and help-seeking

Interviewees in this study expressed a range of attitudes to health, illness and help-seeking. Most people told me that they consider themselves to be generally well. This is unsurprising given that these participants were not necessarily ‘patients’ and many are unlikely to have seen themselves as such in the context of their call to NHS 24, particularly those who had called about somebody else. Nevertheless, I asked interviewees about their own health and attitudes to health in order to understand more about why they decided to call. I also asked about the measures that people had taken to care for themselves or the person they had called about at home before calling NHS 24 and explored how they felt about self-care, self-medication and waiting before seeking help. What is interesting here is the extent to which difficulties in accessing primary care featured in people’s accounts of their willingness to ‘put up with’ symptoms and to self-care; however, this became less relevant when seeking help for someone else.

6.1.1 Attitudes to health and illness

Some interviewees had multiple morbidities and some had experienced considerable ill-health in the past. The conditions reported by participants as present at the time of their interview included diabetes (John, Alison, Nancy, Jim); depression and/or anxiety (Alison, Tina, Paula); chronic back pain (James); Meniere’s disease (Josie); sciatica (Debbie) arthritis (Grace); hiatus hernia and associated stomach problems (Paula, Andrea); Multiple Sclerosis (Grant); anaemia (Natalie); Irritable Bowel Syndrome (Heather) and fibromyalgia (Doreen). It is important to note that in many cases these conditions were not the reason for, or even necessarily relevant to, the participants’ most recent calls to NHS 24; they are mentioned here simply to provide some context for their health care experiences and attitudes.

The majority of interviewees did not seem, on the basis of their accounts, to be frequent users of health services; most said that they rarely contact their GP or NHS

24 and would even more rarely attend A&E or call an ambulance. A very small number of interviewees could be described as having poor general health and relying heavily on health services; for instance John has multiple conditions, attends regular clinic appointments (at least weekly) and has been admitted to hospital so often that he talked about having his own room on the ward. From John's account, it appears that he calls his local A&E, his GP surgery and NHS 24 frequently. Of all the participants, John seems to have the most contact with health services, though Alison also mentioned that she goes to see her GP *'all the time'* and Katie said that she thinks she goes *'quite a lot'*.

There were other participants who have contact with health professionals as a result of ongoing health problems but who said that this tends to be only when absolutely necessary. This group described themselves as more likely to try to manage their conditions themselves without seeking help. They include Andrea, who says she *'just generally keeps unwell'* because of her stomach problems, which she has had for a number of years, and Grace who had cancer in her twenties and now, aged 36, lives with arthritis. Grace has felt badly let down by health services, including NHS 24, in the past and as a result says that she now avoids using them whenever possible.

Some participants who have long term conditions or recurring health problems described themselves as healthy in spite of the presence of symptoms (Blaxter and Paterson 1982; Blaxter 2004). For example, Josie told me about a number of health problems that she has experienced but insisted that she considers herself to be healthy for her age.

ED: *And the, you've just been saying all the things that you've had go wrong, but do you consider yourself fairly healthy?*

Josie: *Yes [laughs- turns into a heavy smoker's cough]. Yeah!*

ED: *You do?*

Josie: *Yeah, I'm, I wouldn't have said that I'm- right ok... in 66 years, ok I had asthma as a child, there were a lot of it about then, you know, eh, this kinda thing, eh... I had an eating disorder in me teens and I still have to a certain extent but who the hell didn't then because we'd all got to be built like anorexic racing snakes, and we lived on lettuce and cigarettes and [indistinct] and all this kinda rubbish, you know, and eh, really, me body's*

done well to cope, wi what I've put it through. Ehm, I had a, a deep vein thrombosis when I were pregnant with Kimberly, ehm, and it broke away when I were in labour and it lodged in me lung, so I were lucky in the respect that I were in hospital, eh, you know but they had to do an emergency section, because they were losin' her, but that were that travellin' through me blood. Now, that's 32 years ago, so that in itself were no mean feat, you know, because they've come on in leaps and bounds wi that kinda thing since. Eh, me appendix ruptured, they took 'em out. Ehm, I'd an emergency hysterectomy cos I'd got ovarian cysts. These are things that are not... they happen for a reason they're not on-going. Right, I have, apart from the Meniere's, which is absolutely nothin' as long as I tek the medication, I don't fall about. But apart from that, I really have done well to get to the age that I am at wi no absolute major things d'you know what I mean?... Yeah I do, I consider meself quite healthy... Yeah, I get, ok, you know I'm kinda like a bit arthritic, ehm, and especially in t' winter, ah cos it's cold, I don't like that. Ehm, and what I used to do in 24 hours, what I used to do in a day it teks me a fortnight to do now, but obviously me body's slowin' down, I'm gettin' old, I can't expect any more.

Josie makes a distinction here between one-off illness events that 'happen for a reason' and ongoing complaints or conditions. This is a distinction that others also made, and it allows people to construct themselves as healthy in spite of the presence of symptoms or illness. Like Josie, Tina had a long list of medical issues that she had experienced in the past but also claimed to be healthy.

Tina: *I'm no really that, an unhealthy person. A lot of things went wrong wi me in ma life but I'm no really an unhealthy person, as such, you know it's just somethin' that's happened to me.*

By externalising illness as something that happens *to* them, Josie and Tina can maintain their self-presentation as healthy and show that they are not to blame for their ill health (Cornwell 1984). Constructing oneself as healthy was important for most of the interviewees, as mentioned in chapter 5, and when asked about their general health people tended to be dismissive of 'ordinary illnesses' and minor symptoms which were considered to be familiar or mundane. Many expressed a functionalist attitude to health (Blaxter 2004) which was related to their ability to work or perform everyday tasks or a stoic attitude (Cornwell 1984) communicated in terms of 'just getting on with it'.

Debbie: *No really, the two ae us are never normally no well. It's just the odd, as I say the odd occasion that, we're either run doon or there is something*

like, serious, nosebleeds. His is mainly nosebleeds and me I just get on wi it. The now I've got sciatica [laughs]. Eh, you still work through it [laughs].

In the interviews, I asked people if they thought that their attitudes to health had changed over their life-course and how they thought family attitudes might have influenced their own. Most participants thought that the way they had been brought up did have an influence, usually in that they felt they had similar attitudes to their parents. They described how they still held the values and attitudes instilled in childhood, for example Josie suggested that she is '*always coping*' because people of her generation grew up '*learning to cope*'. However, there were some notable exceptions to this and they were all young women who felt that their own mothers overused health services. These women defined themselves against their mothers and said that they didn't want to be like them. For instance, Heather said that she doesn't really go to the GP and would '*have to be dying*' before she would go. I asked her if she had always had that attitude.

Heather: *I don't know, I think my mum's a bit of a hypochondriac.*

ED: *Oh really?*

Heather: *So, I think I consciously try and be the opposite. She's got agoraphobia and things and eh, she's always had things wrong, like panic attacks and all this kinda stuff so, I think, I've kind of seen that and I want to be the opposite so I'll maybe not go to the doctors whereas she would go like 2 times a week or somethin'.*

ED: *Oh really?*

Heather: *Ehm so yeah, maybe I'm tryin' to be the opposite. That's maybe my problem, yeah, I don't want to be a hypochondriac.*

Heather raises the image of the 'hypochondriac' here, which, as discussed further below, was an undesirable label that a number of other participants mentioned and were also keen to avoid. For most of them, contacting a health service was an unusual step. Many said that they would '*suffer*' or '*put up with*' minor symptoms, or wait for their illness to pass. Many would also take steps to care for themselves or their children at home.

6.1.2 Self-care and self-medication

Most interviewees had attempted to care for themselves or to seek help elsewhere before contacting NHS 24. Their actions included waiting for a while to see if symptoms would ease; taking (or giving children) painkillers or other over-the-counter medicines such as antacids or antihistamines; looking for information online; or trying to call someone else such as a family member or their own GP. Only 5 people had not done anything prior to calling: Tomasz, Grant and Laura were all worried about small babies and felt they needed immediate advice; Doreen didn't know what to do about the swelling on her hand because it was something she had never experienced before; and John, whose nosebleeds are a recurring problem, called NHS 24 straight away because that's what he always does in that situation.

I asked interviewees about the kinds of steps they usually take to care for themselves or their children when they are ill. As noted above, many talked about '*just getting on with it*' or '*just suffering it*' when they experience minor symptoms, though some also mentioned using a range of over-the-counter medications or home remedies which they had learned about from family, from books or from health professionals. When prompted, some interviewees said that they would ask a pharmacist for advice about illnesses such as coughs, colds, flu and hay fever. Maggie said that she has previously spoken to a pharmacist when she has wanted advice during the working day, but doesn't know how to find out which ones are open at night. Matthew said that he would ask a pharmacist for advice about symptoms but also said he would be less confident in the quality of advice available now that his local pharmacy has been taken over by a large chain. It was interesting that more interviewees did not say that they would consider seeking advice from pharmacists given the expanding role of pharmacists (Scottish Government 2013) and also given that many of the concerns expressed about self-care related to either prescription or over-the-counter medications.

Self-medication

Before their most recent call to NHS 24, some people who had painful symptoms had taken paracetamol or other analgesics and this seemed to be usual practice for many.

Interviewees showed varying degrees of understanding of over-the-counter medicines; some had a comprehensive understanding of when to use a range of medicines, while others would not take anything at all without seeking medical advice. For those who had not used any medicines before calling, there were a range of reasons given, including worries about drug interactions as well as beliefs about medicines and attitudes to taking them.

John, Alison, Nancy and Jim all described being reluctant to take any medication (other than paracetamol in some cases) without seeking medical advice because of the medication they are already on for their diabetes or other illnesses.

Alison: *Cos I'll no even take any other tablets unless I see ma GP because I'm on that much medication in case it interferes wi all ma medication [...] and if they gie me new medication, I'll always ask them if it'll interfere with all the medication that I'm takin', cos I'm on a lot o tablets.*

Likewise, although she had been in pain, Ingrid hadn't taken any painkillers before contacting NHS 24 for the same reasons:

Ingrid: *No because I didn't, I'm eating into so many pills every day that I just expect a revolution if I add anything to it, you know, without somebody telling what to do [laughs]. Ehm, you know this is the trouble.*

Others described being reluctant to take over-the-counter medications because of their beliefs about how they work and their effects. Tracey said that she tries not to take tablets unless she 'really has to' because she thinks that 'if you take somethin' too much you'll end up gettin' used to it', while James feels that masking pain can be dangerous:

James: *I don't actually, I don't, if I'm bein' honest with you I hate takin' any tablets at all, eh, unless I have to like eh, I- I'm just, I'm dead against takin' ta- I al- see I always feel, if you're takin' tablets for somethin' like a pain in your back, you're only maskin', that's ma personal view is you're no actually gettin' to the root problem, you're only, you're numbin' it down, I mean you might be doin' damage, that's what I think. Could be wrong obviously, the doctors'll know better than me like, but, and as I say I only take painkillers if I have tae. Ehm, I mean I, I have got some ae the painkillers left, that I, well, some of the ibubrufen [sic], the rest of them I finished I had co...drydamol I think it was I finished them, I now have ibubrufen left but, I don't wantae take*

them cos I know for a fact they give me an upset stomach. But they're there if needed like, if I'm in pain I- I would probably take one like.

James' attitude to the use of painkillers was particularly interesting given that he has a chronic back problem and when he is in pain he knows that nothing will help other than strong medication. However, he still seeks medical attention rather than keeping painkillers in his house and self-medicating, something which I explored with him further:

ED: *So do you think if, if that was to happen again, that you would end up ringing NHS 24 again or do you think you'd know that they were gonna say take certain tablets and just go ahead and take them or, what would happen?*

James: *[sighs] If I'm bein' honest I would probably phone NHS 24, probably, because, I know what you're sayin' it would probably be easier if I kept the tablets in the house and tried them first but... it's like, either that or I would probably just go over to the hospital again. Ehm... Aye I understand what you're sayin' it's like aye it would be easier to keep them in the house but, at the time it just feels like, the tablets I've got aren't strong enough eh and it's like I need somethin' stronger because the pain is so, chronic. But eh, I must admit I would probably phone NHS again.*

The impact of people's understandings of medications is significant in terms of their ability to care for themselves but also in terms of their understanding and satisfaction with medical advice. Part of the reason for Robert's dissatisfaction with the advice that he had been given by NHS 24 was that it didn't fit with his understanding of painkillers and the types of pain they are suitable for.

Robert: *Aye, takin' painkillers for sore stomachs is crazy to me, it just makes things worse, some of these painkillers can knock 10 bells outta my stomach, anyway, you know even when it is good. I ehm, don't take them unless it's really necessary.*

ED: *Right, is that just generally, if you had a headache or somethin' would you take them?*

Robert: *Aye, a Solpadeine, I take Solpadeines, when required, and I find they're quite easy on the stomach, they don't upset the stomach so bad. So they're, we generally keep a pack of them in the house all the time, eh, for headaches and like, you know, if you feel a bit, a sniffy cold or anythin' like that, you're feelin' a bit rotten, paracetamol helps.*

Some people were quite reflexive about their attitudes to medication, and the reasons why they don't like to take any. For example Tina has a history of childhood kidney

and bladder problems which meant that she had to take regular courses of antibiotics and she now describes herself as ‘*really bad for takin’ tablets*’:

Tina: *I had a lot ae infections, I lost a lot ae school through it. A lot of kidney infections, [...] even they’d say you’re goin’ on antibiotics I’d go ‘Oh god’, you know, so I try to avoid, I mean I don’t even have Disprin in the house, I don’t have anythin’ like that in the house. Try to avoid takin’ tablets, shoved down ma throat that often when I was a kid I try to avoid takin’ medication if I can avoid it. I’m no prone tae headaches and things thank god.*

Some people with long term conditions described how they prefer to manage their symptoms without medications where possible, particularly through diet. Paula and Andrea both try to manage their hiatus hernias by eating carefully and Grant also uses diet to manage his MS. Tina spoke a lot about ‘*knowing what her body needs*’ in terms of nutrition and Gail said that she and her family rarely get ill because she ‘*packs them with vitamins*’. Grace said that she has not found medication helpful in managing her arthritis and has particularly struggled with side-effects.

Grace: *I don’t find the tablets work for me, ehm... I don’t like taking the tablets because you have to have tablets for taking the tablets and, I don’t believe that they can help me long-term. I’ll have to go on tablets I think when I get older, but now I’m trying to manage it myself*

Instead, Grace has done a lot of research into nutrition and has been able to improve her condition through a combination of diet and acupuncture, although she does still see her GP and takes medication when experiencing severe pain. This sort of medical pluralism was not uncommon in interviewee’s accounts, with others also reporting use of a mixture of biomedicine and complementary or alternative therapies.

Although use of non-prescription medication is widespread in Scotland (Porteous et al. 2005), the attitudes expressed by some participants here are similar to those found in earlier research where people were against taking medication due to beliefs that it would lead to decreased efficacy and that it would dull problems rather than dealing with them (Calnan and Williams 1996; Britten 1996).

Medicating children

Use of over-the-counter medications for children is also widespread, but many parents are unwilling to give children medication without prior advice from a

clinician (McIntyre et al. 2003; Trajanovska et al. 2010). Interviewees in this study who were parents were generally cautious when it comes to giving medicines to children. For example, although Claire would take something herself if she felt unwell, she finds that there are fewer over-the-counter medicines suitable for children.

Claire: *But with a child because you can't really give them very much, it's very hard to, like I would never even try and treat, prescribe anything for them, just because, you know I'm not a medical person. But yeah, no for myself I'll sort of try and self-prescribe.*

Others also highlighted the limited availability of medicines suitable for children, and thought that changing guidelines about things like dosages and suitability for babies mean that the options are narrowing.

Andrea: *I'm... he's got the cold just now, but because of his age there's- there's nothing that you can give him now, ehm whereas before it was always kind of like Medised but now that's 6 and over, so, they basically say, well, just give him a wee drop of Calpol, or, let it run its course...*

Again, some people were quite reflexive about their attitudes to medicating children. For example, Heather feels comfortable giving her children Calpol if she thinks they need it but said that her husband is reluctant to give them anything and she linked this to his own upbringing.

Heather: *[...] the way my husband is too, it's like ehm, he was raised to just get on with it, nobody was ever ill in his house, and he's very much like that, ehm, he won't give them Calpol and things, you know-*

ED: *Really?*

Heather: *My first thing would be, like if they're not feelin' well or she's got a sore tummy, I'll give them Calpol, whereas he'll ehm, he'll say 'Oh they've not been feelin' well today' and I'll say 'Did you give her Calpol?', 'No' and he just won't think, he'll just say 'You'll be better soon' and that's it. He'll leave her, yeah. Whereas I'll have to give her Calpol and then I'm thinkin' 'Am I bein' a hypochondriac? Is that startin' to come out in me?' [Laughs]. So, but I'm not, I'm not. I think when it's your kids you can't- [...] it's only a bit of Calpol, it's not, yeah it's not eh, and it'll help them as well so-*

Even though Heather would be happy to give her children Calpol she feels differently about antibiotics, although she is not clear on her reasons other than vague worries about overuse.

Heather: *Whereas I would rather never, the kids have never had antibiotics, I'd like them not to, I don't know why. You'd often hear people saying that you can have too many, so I'd just rather they didn't have any if they don't need them. Yeah. And I like them to have lots of mud, and dirt [laughter], try and boost their immune system, if that's true.*

Tomasz and Irena hadn't given their baby any medication before their recent call to NHS 24, even though they were worried about his high temperature. Irena explained that because the baby's behaviour was unusual, she didn't know what to do.

ED: *And was there a reason why you hadn't tried to give him Calpol beforehand?*

Irena: *Eh, it was, just like I said because he was behaving in such a strange way, so it wasn't only that I was thinking that he has fever but it's alright. I thought it's fever and he doesn't act normally, he behaves in a different way, so I thought like ok, you know, we'll just get advice before we do, really do anything, really. That was my thinking behind it anyway.*

For Irena, a straightforward temperature might have been something she could have dealt with, but because the baby seemed lethargic and this was not something she had experienced before, she was unwilling to do anything at all. She did give him Calpol after the call, on the advice of the NHS 24 nurse.

Similarly, Grant and Jodie had not given their baby any medication before calling NHS 24, although she had injured herself and seemed to be in pain. Again, this was because they didn't know what to do and were worried about potential interactions:

ED: *Right, so had you given her any painkillers or anything like that? Given her anything?*

Grant: *Ehm, not at that point ehm, as far as I remember. Ehm, just in case, you know, we were advised to, to maybe take her up to, to the hospital at [town] for, for any, for a check over and then if that required any sort of medications to be given then didn't want to have already given her something that might interfere.*

While use of over-the-counter medications is a significant component of many interviewees' self-care practices, these findings suggest that a lack of knowledge about medications and lack of confidence in self-prescribing is restricting the level of self-care that people are willing or able to engage in.

6.1.3 Attitudes to help-seeking: waiting

In the focus groups and observational fieldwork, the idea was repeatedly expressed that in our modern, 24-hour society there is an expectation of instant access to services, including health care. Some respondents thought that young people in particular are unwilling to wait any length of time before seeking help. I explored this idea in the interviews, asking participants how long they had waited before calling NHS 24 and how long they would usually wait with a symptom before seeking help. In this sample, there were no clear patterns to suggest that any demographic group is more likely to wait or more likely to want immediate attention. Rather, individual attitudes combined with the nature of symptoms led some to seek help more quickly than others.

Some older people, such as Ingrid (in her 70s) had sought help almost immediately when they experienced symptoms while some young people had waited for a considerable length of time before seeking help. For example, Andy (24) had diarrhoea and vomiting for 5 days before he called NHS 24 and Lauren (21) had a lump on her side for several weeks, only seeking help when she experienced severe pain. I asked Lauren if she would usually wait that long before seeking attention for a symptom.

Lauren: *Well, I've never had anything like that before. Like I'm generally quite a, I always have been very healthy, I've never been to hospital, never had to do anything like that before, so... I don't know, really, I probably would just leave it and leave it and leave it, until, until it got so bad that, like that I had to phone NHS 24. But I mean I just thought, cos I thought 'Oh it's just a pain in my side, like it won't be anything', I hadn't noticed there was a lump there until I was like, massaging it, trying to make it feel better and I was like, 'Oh, there's definitely a lump there'. And then I was a little bit concerned but I was just like, well, maybe it's just there, I don't know, and then, but then, I didn't, cos my GP's at home in [town], I don't really have the option to go to a GP around here, so I just thought I'll book an appointment for when I get home, but then it was really bad on that Thursday*

so I had to phone NHS 24 anyway. So, maybe, I don't know, I honestly don't know whether I would have left it longer or not, if that hadn't happened. I probably would never have done anything about it.

Lauren told me that she had once waited for about 8 weeks before going to her GP with symptoms of glandular fever but, interestingly, she also said that she would go to the GP straight away for something 'cosmetic' like impetigo. Reflecting on this, she thought that because it is a familiar symptom and she knows a prescription cream will clear it up quickly, she is more likely to act immediately. She thought that her willingness to put up with symptoms 'would just depend on what the actual illness was'. However, she also thought that people of working age probably would want immediate attention if they needed it, and that once she finished her studies she might also be less willing to put up with symptoms.

Lauren: *Mmmhmm, whereas I would, like I know that when I'm working next year, for my training year, I won't have time to be unwell, so if I'm not well and I need medication, then I'll go straight to the doctor.*

This idea that working people don't have time to be ill was expressed by others, although for some it would make them less, rather than more, likely to seek help if they could avoid it.

Gail: *I think, you know, I went for months with a tooth that crumbled and had no fillin' in it and I was in agony, and I eventually phoned the emergency dentist, my face was out here. And I put up wi it and put up wi it for ages before I would like, phone them, and the guy just filled it, he put a dressin' in it and filled it and then told me I'd have to phone NHS 24 again if I needed anythin' else. Well, it literally, ma whole tooth crumbled and it all be left with is a shell. I was in that much pain, and I kept- I got through Christmas and New Year and I thought, oh I have to do somethin', I have to do somethin', but gettin' a day that I was off work or that I was able to just drop everything at you know, the drop o a hat, was, well I just dinna get days like that.*

Another reason given for not seeking attention for symptoms quickly was that when people don't think symptoms are serious they will 'save things up' and seek advice about 2 or 3 things during a single GP appointment. Maggie and Irene both said that they would do this because they don't want to approach their GP about something 'trivial'. However, Maggie suggested that NHS 24 is 'more available' and that she is more comfortable calling for advice about a symptom that she would otherwise 'save

up'. This makes sense given that one of the main reasons that people gave for delaying seeking help when they are unwell is the effort involved, particularly where access to GP services is seen as poor which was quite common, especially in urban areas. People described trying to get an appointment as 'a nightmare', 'a hassle' and 'very difficult'.

6.1.4 Attitudes to help-seeking: access to primary care

Declining access to primary care is one of the biggest differences that people had perceived in the health system over their lifetimes. Many of the older interviewees could remember a time when GP surgeries did not run an appointment system but rather people just turned up and queued. Doreen thinks that the effort involved in accessing appointments now makes people less likely to seek help:

Doreen: *But, eh, I think, eh, I think people relied on their doctors then, I think they, they went there for things, you know. Now, you think, och, I'm not going to get an appointment, I'll maybe just leave it just now. You know, that's, you know, see if it'll get better. Maybe no everybody would do that, but I would if it wisnae, I wisnae too worried about it, you know. But some things you think, 'Oh, I need to get an appointment', you know, and then you're still waiting maybe 2 weeks or something because you're, I'm sitting near that phone waiting for half 8 to get on, and I'm lifting the phone and I'm dialling their number and it's engaged and I just keep redial, redial, redial til I get through, so I've seen it being 9 o'clock, eh, 20- eh, quarter past, 10 past before I get through, 'I'm sorry, I havnae got anything for today or for the next, next week or 2'.*

Even those who had always used the appointment system felt that access was getting worse. Many participants reported difficulties getting through to their surgery to make a same-day appointment and waits of up to 2 or 3 weeks for a non-urgent appointment. Debbie and Euan even described being told they would have a 2 week wait for a telephone consultation. Participants said that the effort involved in getting a GP appointment would put them off doing so unless it was 'really necessary', but some reflected that they usually only seek appointments for things that they feel are serious anyway. This makes the idea of waiting for weeks even more problematic.

There were some geographical differences in perceptions of access to GP services in that it was not seen as so difficult in some rural areas. Steven and Julie live in a small village in a very rural area:

Steven: *Our local doctor you can phone up in the morning and you can usually get an appointment that day, or within a couple of hours cos it's only a small area. So you don't have to wait days and days for appointments. Quite lucky that way down here. It's very ra- unless it's a weekend, you never really, or nights, you don't wait.*

Robert, who lives on an island, thought that people in the more remote parts of the island might find it difficult to get to a GP because of distance, but that in the bigger villages and towns it was easy to just go to the doctor. He did say that in his local surgery you could wait weeks to get an appointment with your own GP, but that you could get an appointment quickly if you were willing to see any doctor. He didn't seem to think that pressure on health services had as much of an impact in rural areas.

Robert: *I think we get a better service here from doctors, and dentists as well, than you would normally get in the town, ie likes of Inverness, you would need to go to the A&E I would think, you know for anything, you wouldn't be able to, I don't think you can contact a doctor in Inverness out-of-hours, you would need to go to hospital.*

ED: *Why do you think that is?*

Robert: *Well it's just them changin' - cutbacks as well. Ehm, and they want more, more social life as well, not gettin' pulled out in the middle of the night, ehm plus there's some things that are fairly trivial I suppose.*

Even those with poor GP access usually said that they would still try to call their surgery, if it was open, before calling NHS 24. For those who consider NHS 24 to be for emergencies only, this is because trying the GP surgery first is seen as the appropriate thing to do. For example, Andrea doesn't think that she has good GP access and described a similar experience to that recounted by others of phoning at 8am to try to get a same day appointment, but she said that she would still rather do that than phone NHS 24, which she considers to be '*a last resort*'.

For a small number of people, the reason they would always try their GP first is that calling NHS 24 was seen to be a waste of time if they thought they would need to be

seen anyway. For example, although Anna complained about how difficult it is to get an appointment at her surgery, she said that it would never occur to her to phone NHS 24 if the GP surgery was open. Her husband Peter disagreed and thought that he would phone NHS 24 as a first port of call regardless of the time of day.

Peter: ...but, yeah I mean I would certainly phone NHS [24] before the doctor's because, eh, today for example you've sat up in the waiting room for, for how long?

Anna: An hour 20 minutes-

Peter: Whereas you can get someone to tell you over the phone, ask you the questions over the phone and tell you whether it's worthwhile goin' to the doctors or not. You know that's better use of the doctor's time and better use of my time, and better use of everybody's time really isn't it, so... You know what I mean?

Anna: I- yeah, I agree but, I mean the times I've phoned NHS 24 in the past, which I have to say I'm not criticising at all, cos I think it's a very good service, but it's just it takes so long to go through the sort of, obviously the flow chart, you know the yes/ no answers and you're just like that 'Oh for goodness sake I could just be up at the doctor's with her, for them to look at it'.

Unlike Anna, most of those who think that their GP practice is inaccessible said that they think NHS 24 is a better way of getting advice quickly.

Heather: NHS 24 would be ma first choice, unless it was obviously an emergency.

ED: Yeah.

Heather: Ehm, I think even before I'd call the doctors I would probably do that, because you get an instant kind of, you don't have to go and make an appointment, do you, or wait, or get them in the car, [indistinct].

ED: Yeah, and would you do that even during the day?

Heather: Yeah, I would do that during the day I think ehm, I don't feel like calling the doc- I don't feel like they're ehm, that available, to call the doctors. I feel like they're only, if you call the reception they're more for appointment making, I don't feel like I would call for any advice from the doctors at all. Ehm, ma mum makes phone appointments with the doctors, but I don't really, I wouldn't do that.

Heather's comment here highlights the difference between just wanting advice and needing an appointment and this distinction was noted by others as a factor in their decisions about where to seek help. Natalie also saw NHS 24 as a faster way to

access advice but she would make an appointment with her GP if she thought she might need a prescription.

Natalie: *If it's something like, you know, like an actual illness like tonsillitis or something I feel that I need antibiotics for, then I'll go to the doctor's, but if it's advice I'll phone NHS 24.*

ED: *Ok, and why is that?*

Natalie: *I just, I find it's a lot quicker to get advice. It's, ehm, it's obviously, you will end up speaking to someone. Ehm, and sometimes when you do want advice, you want advice right then, you don't want to wait 2 weeks for a doctor's appointment over something which might be absolutely nothing. Ehm, yeah.*

Overall, it is clear that perceptions of access to health services feature heavily in many participants' decisions about how to deal with symptoms and in their assessments of both the most appropriate and the most convenient route to care. However, a broad variety of attitudes were expressed and while some see calling NHS 24 as a way to access services or avoid making a GP appointment, others see using it in this way as inappropriate. This is unsurprising in light of the range of perceptions of NHS 24 illustrated in chapter 4.

6.1.5 Seeking help for others

While people said that they would often put off seeking help for themselves because of the effort involved and a willingness to 'put up with' symptoms, most said that they would not delay seeking help for a child or vulnerable adult. The reasons given were usually that children are unable to communicate the severity of their symptoms, that they can deteriorate quickly and that there is an added responsibility when making decisions about somebody else. Almost all interviewees who are parents or carers expressed this view. For example, during my interview with Peter, his wife Anna returned from the GP with their 3 year old daughter. She had made the appointment a week and a half in advance and had then waited for an hour and 20 minutes in the waiting room.

Anna: *And, we went up there but as soon as we went in, the place was packed and you just think, oh, they're goin' to be late with their appointment and it just puts you off, it really does, I think, I wouldn't hesitate with the*

children, but when it came to us, d'you know, we just, we're never really there are we, cos it's just such an effort.

Jodie also said that she would take action more quickly for her daughter or for her husband, Grant, who she sometimes cares for:

ED: *Why do you think that might be?*

Jodie: *Ehm, in short probably hassle. [Laughter] Something else, it may be something else to do... like I would probably wait until I really need to go to the doctor's, to take myself. Ehm, because it's a, it's getting time off work, it's fetching Ellen to nursery, it's...ehm... Whereas if I think Ellen needs to go to the doctor then she goes.*

Some of the women who said that they would not usually contact NHS 24 or their GP described how the only times they had done so were related to pregnancies. It was interesting how they distinguished between their own health and that of the foetus in these accounts; they could construct their health service use as legitimate in these cases by claiming that it wasn't really for them.

Heather: *Yeah I don't really go to the doctors about things. Sometimes I feel like it's a bit of a hassle, or a fuss, like you're makin' a fuss, when there's people like with cancer and all this kinda stuff out there, so, maybe I need to recognise the med- sort of middle ground, cos I don't really, I would have to be dyin' before I, or like, when I was pregnant I called NHS 24 it was because I was, it was the baby, it wasn't really for me, ehm, so yeah for me I would leave it. Yeah.*

Claire: *The only times I've been to the doctor over the last 5 years is pregnancy related, and that's for, eh, appointments that you have to go to. Ehm, for the first child we ended up in the, in the maternity ward a couple of times due to pains and stuff like that, but that wasn't, that wasn't myself [whispers] that was the baby! [Laughs]*

While people generally said that they were quick to seek help for children, there were some situations in which they would be willing to wait and try home care. This tended to be once they were more experienced and familiar with symptoms such as temperatures, colds and stomach bugs, or illnesses which their children experienced frequently. For example Gail's daughter has recurring urinary infections and her son has asthma.

ED: *And do you feel quite confident in like, looking after things like that with them when they get like, things like urinary infections and things like that?*

Gail: *Ah yeah. Because it's happened that often, I know the first thing I need to do is put a sample in, so I always have a bottle wi me, ehm, urine sample straight to the doctor for her, and they just hand me antibiotics, straight away, you know, and Craig's asthma, well there's not much they can do, they'll not gie you ehm steroids, and a lot o the time, it can just be, you know over and done wi in a few days so there's no point phonin' the doctor for. And if there i- I mean if it does worry me then I will, if it continues on for longer than, say 3 or 4 days then I would phone the doctor and say well look this has been goin' on.*

Parents also said that they would be more likely to watch and wait for a while before seeking advice about symptoms if the child did not seem to be distressed. Behaviour change in children was mentioned as a key factor in many parents' decision-making about symptoms, as has been found in previous studies (Blaxter and Patterson 1982; Cunningham-Burley 1990; Cunningham-Burley and Maclean 1991). The need to seek help more quickly for a child or a vulnerable adult was strongly linked to ideas of responsibility, but, as will be explored in the next section, the responsibility not to take risks with health can sometimes conflict with the responsibility to use health services appropriately.

6.2 Responsibility

During observational fieldwork and in the focus groups and interviews, the view was often expressed that people need to '*take responsibility*' for their health. Some respondents were particularly disparaging of what they described as the '*nanny state*', in which there is seen to be too much reliance on public services and professional advice and too little self-reliance. When people discussed personal responsibility for health there was an emphasis on diet, nutrition, exercise, and only using health services when really '*necessary*'. There was also an emphasis on the importance of being aware of one's own state of health and taking responsibility for staying well, or getting better when ill, echoing the neo-liberal discourse of self-surveillance and responsible citizenship discussed in chapter 2.

As the previous section has shown, most of the callers I interviewed had taken steps to care for themselves or their children before their most recent call to NHS 24. They

describe self-care as part of their usual response when dealing with symptoms and say they only seek help when they consider it necessary. Most participants seemed acutely aware of a need to be, and to be seen to be, responsible users of health services. I found that participants went to considerable effort to construct themselves as responsible and to distinguish themselves from the ‘other’ who wastes time or resources. They did this primarily by recounting stories of their own responsible use and by highlighting examples of the irresponsible or wasteful behaviour of others.

However, while ideas about taking responsibility for health centred on self-care and the responsible use of health services, there was also an awareness of the need for individuals to avoid taking unnecessary risks with their own health or that of their children. This means that people must sometimes balance the competing imperatives of being a responsible health consumer (avoiding unnecessary use) while also being a responsible patient or carer (seeking help in a timely fashion).

6.2.1 Views about ‘inappropriate’ use of health services

In the interviews, I explored people’s ideas about what they considered to be misuse or inappropriate use of health services. While I sometimes prompted by asking if they thought that particular demographic groups use health services more than others, it is important to note that I and the interviewees differentiated between ‘more frequent use’ and ‘inappropriate use’. For example, some people thought that older people use health services much more than any other demographic group but that this was because they have more health problems and therefore greater need; their use was not seen as inappropriate. The link between perceived need and appropriateness is important and there were strong moral discourses (Zola 1972; Locker 1981; Cornwell 1984; Lupton 2012) apparent in discussions of this topic.

***Natalie:** I think, yeah... I mean I think if somebody needs medical help then they’re not a drain. I think if people, well if they need medical help because of a medical reason, then they’re not a drain. They’re just using a service provided for that reason. Whereas if somebody has got themselves into a situation due to irresponsible behaviour, then that’s a waste, that’s a drain. Those are resources being taken up that didn’t need to be.*

Natalie's reference to '*a medical reason*' is notable here. Legitimate use was strongly linked in many accounts to not being responsible for the symptoms or illness. When interviewees spoke about who they think is likely to misuse health services, many mentioned '*drunk people*' and '*people with addiction problems*', illustrating a focus on social characteristics rather than medical seriousness (Jeffery 1979; Cross et al. 2005) when considering who is deserving and who is undeserving of health care. There were some mentions of people who '*play the system*', such as those who fraudulently seek medical evidence to claim benefits and some interviewees linked both overuse and inappropriate use to unemployment.

Irene: *You know, it's- I think when you're working, and you know, you just tend to get on with the job and do the job and you don't have time. But if you're not working there's possibly too much time to think, 'Oh I've got this, got this terrible pain' and a lot of it can be caused by the stress of not working and not having a purpose, you know. But I, I mean, I'm only, I'm just sort of reflecting what I've heard on t- you know, things on TV. You know you do see these programmes and you think, my goodness, they're phoning and, you know, there was- I can't remember, somebody couldn't get their bra fixed or something, you know, you're like that, I don't think so [laughs]. I don't think that's something I would be calling the NHS for.*

Similarly, Julie believes that her GP surgery is flexible with appointments on the basis that their patient group are not '*time-wasters*' because they are in work.

Julie: *And I've seen them fit you in, they finish at 6 I think, and they'll fit you in, even, depending if you've got a kid they're- cos they know, there's no many time-wasters up here. Again, I'm sayin' that because maist of them are all workin', you know, they're all- again up here's mainly a workin' community up here. There are thae big villages now, nae disrespect to some of them like, some of them just havenae got jobs, some have got jobs, you know eh, so when they're up here they tend not to go to the doctor's until they're eh, really, really need it, and then their hand's hangin' off!*

Interviewees also mentioned '*attention seekers*' and '*hypochondriacs*' in the context of discussing inappropriate use of services, particularly in relation to people who make '*unnecessary*' GP appointments. This caused particular annoyance, perhaps unsurprisingly as it has a specific impact on people's own access to health services. Doreen, for example, said that she thinks some people are '*a wee bit hypochondriac*' and '*just go [to the GP] for nothing*'. Josie sees this as something

that has worsened over time and she thinks that people are ‘*more hypochondriacs now*’ than they were in the past.

Josie: *Eh but I do, I think, and I think people are turnin’ more into hypo- they go to the doctor’s with the slightest little thing... that’s not- well to me, it’s not, I wouldn’t, I don’t know people are different, it could be sommat major to them but, like I say I were brought up in a different era.*

It is notable in the 3 previous quotes that Irene, Julie and Josie all qualify their comments with a recognition that they could be construed as judgemental; Irene acknowledges ‘*the stress of not working*’ as a potential causal factor and distances herself from her views by saying that she was just reflecting what she heard on TV, Julie acknowledges that some people ‘*just havenae got jobs*’, and Josie concedes that ‘*people are different*’ and may have different views on the types of symptoms that need attention. This was common in many of the interviews, and I found that people were far more reluctant to comment on the motivations of ‘others’ in individual interviews than they were in the focus groups.

Some people were uncomfortable with the line of questioning about inappropriate use, seeing it as ‘*loaded*’, ‘*very complicated*’ and a difficult ‘*debate*’. For example, Grace had to be prompted to engage with this topic and although she clearly had strong views, she attributed some of them to her husband and suggested that she was only commenting in response to my prompts, as demonstrated by her slightly defensive question ‘*is that what you want?*’

Grace: *I dunno [long pause] um...no, that’s difficult. Say for instance when I was pregnant, I used to look out the window of the hospital and see the pregnant women in the bus shelter smoking. That’s a thing I don’t agree with, that the NHS should look after these people, when they’re smoking away, damaging the child and there’s noth- no consequence, ehm. I get annoyed at that. I get annoyed at, well my husband gets annoyed at people coming into the country, he’s worked really hard, he’s getting things taken off him. Yes they’re here for, it could be awful in their own country but, we need to look after our own people and they’re not being looked after. It’s very complicated, very difficult. Ehm, is that, is that what you want?*

In almost every case where people were critical of what they saw as misuse or inappropriate use of health services they were careful to qualify their comments in

similar ways to those noted here (and elsewhere, see Cross et al. 2005). This may be because they didn't want to be perceived as judgemental but also because they thought that it is not always obvious why people are using health services and that they are likely to have, or at least to believe they have, a genuine need. This is illustrated by Anna's position in the below conversation with her husband Peter.

Peter: *I think a lot of people have just got the habit you know as I say they, they, there's somethin' wrong with them and they don't think twice about phoin' the doctor's and goin' up to get a, an appointment, and, and there's a lot of people that are in that habit, and I think it would be difficult to get them out of that. Ehm, but as I say it's not somethin' I've ever... As I say I very, very rarely feel the need to, to phone the doctors and ehm... yeah I think there's a lot of people, whether it's just for attention on what, I know there's a lot of people from a lot of different backgrounds, and... yeah, it will be those that as I say they sneeze, they think they'll phone the doctors, ehm obviously there's a lot of people that have that, sort of outlook and, you'll never get that out of them. As I say, the times that I've been in the doctor's you can tell just lookin' round the waitin' room who's kinda, should be there and those that clearly shouldn't be there, eh, so there's, there's a lot of underlyin' issues as well and things you can't see from lookin' around in a waiting room, ehm, but yeah you... you can see or get the general feelin', impression that there's a lot of time-wasters that are in there. Ehm, don't need to be there, but as I say they've got the- That's just my impression.*

Anna: *I think that's quite unfair, personally but-*

Peter: *That's just my feelings, but, as I say the doctors are there to sorta look after those that really need to be looked after, not, I know that there's a lot of sort of time wastin', and-*

Anna: *Yeah but if somebody's like, been stabbed and they're completely bleedin' or they've got limbs hangin' off, they're not gonna be sat in the doctor's waitin' room are they?*

Peter: *No I'm not talkin' like that, I mean-*

Anna: *They'd be at hospital! You know so most people that go to the actual doctor's waiting room, they are going to look like there's nothing wrong with them for a lot of people. But, you know they're there for a reason.*

Peter: *Well, mebbe in their own minds, but I'm sure the doctor... a good percentage of the time would say differently.*

The link between what is considered to be irresponsible use of health services and stigmatised behaviours such as smoking, drunkenness and drug use is a significant one. Natalie's example of what she considers to be misuse illustrates this link clearly. She portrays her own visit to A&E as legitimate, even though it was the result of a

'ridiculous accident', because she and her friend were both sober. She distinguishes this clearly from attendance as a result of alcohol use as she considers drunk people to be more responsible for their situation.

Natalie: *In terms of who I think is wasting resources... [long pause] I would- once I had to go, um, to [hospital], with a friend, who had broken his rib falling off a swing, and it was late and we were both sober, it was just one of those ridiculous accidents, and we went to [hospital], and we were in A&E, and there were so many drunken teenagers there, and I actually felt a little bit ashamed of the human race [laughs]. I felt... that, these problems should never have been here, this is not how it should be... I think that, was the biggest sense of waste [laughs].*

ED: *That they were teenagers, or that they were drunk, or that they were drunken teenagers or-?*

Natalie: *Eh, I think, more the drunk, cos there were older people there as well, and it was just... I just felt it was just so irresponsible... I think, and if I was to be brutally honest, I think I'd probably admit a negative bias towards alcoholics and drug addicts, who, I know they have the same right, to the, like health care, but on the other hand I don't feel they should be going out their way, well not going out their way but, I don't feel they should be getting their selves into the situation where they should be getting things wrong with them.*

Another story told by Natalie shows how strongly the attribution of blame can determine help-seeking behaviour. Her view that being drunk makes people responsible for their own injuries and therefore less entitled to care led to her being reluctant to call an ambulance even when her husband was unconscious.

Natalie: *Ehm, once, my husband's friends brought him home with, like a huge cut and a massive bump, while he was passed out. I phoned NHS 24 for that.*

ED: *Right?*

Natalie: *They sent an ambulance [laughs]. Ehm-*

ED: *Why did you phone NHS 24 that time?*

Natalie: *Because, it was out-of-hours [laughs], ehm, and, I didn't know if, I would feel really uncomfortable with phoning 999, for anything short of, like for heart attacks ok, but for... I wouldn't have called 999 in that situation.*

ED: *No? Even though he was unconscious?*

Natalie: *Ehm... yeah [laughs]. It could have been that it was self-inflicted, the unconsciousness, and could not be related to the head-wound, there's always the possibility that they were 2 distinct events [laughs].*

As well as the type of person that is likely to misuse services, the types of problems which were considered inappropriate for health service attention were frequently those that are easily identified as not being serious medical issues. Typical examples came from TV programmes such as ‘999: What’s your emergency?’ demonstrating the extent to which medical dramas as well as factual and news items ‘serve to reproduce major currents in the broader society and to contribute to “ways of seeing”’ (Lupton 1998: 204).

Euan: *Unless you get aw the idiots as Debbie says, who ends up phonin’, like the ones we watch on the telly and everythin’.*

Debbie: *Aye, the yins that phone and ‘I’ve got a splinter’*

Euan: *‘I’ve got a splinter’ or ‘I cannae get ma key in the door’, ‘I’ve jammed ma finger in the door but it’s no bleedin’.*

Julie: *I don’t know if you’ve seen it, it’s a Blackpool thing we watch, and folk phone up for the stupidest thing, 999 calls, and doctors on call and all that, pfff, half them are no needin’ it. You know, cannae get their shoe on or, things and you think ‘God almighty’, but I hate it.*

These sorts of examples are common in media reports (BBC News 2014) and are used to highlight the problem of ‘time-wasters’. However, such extreme examples create a distance between ideas about what is considered to be inappropriate and the reality of everyday decision-making about symptoms. The constant media attention to misuse of the ambulance service and emergency departments may also contribute to a sense that other health services are unlikely to be misused. Certainly this seemed to be the case in interviewees’ accounts as only Julie and Steven gave an example of what they considered to be inappropriate use of NHS 24; people calling to get access to a doctor out-of-hours because ‘*they don’t like the doctor that’s on*’ at their own surgery. In addition, it is notable that so many of the examples of ‘inappropriate’ use or ‘misuse’ of health services given here concern ‘other people’. Unsurprisingly, people did not usually consider that their own use of services may be inappropriate (Adamson et al. 2009) although some were aware that their symptoms may be seen as trivial from a clinical point of view (Roberts 1992). Nonetheless, as these accounts demonstrate, considerations of appropriateness do feature in people’s decision-

making about calling NHS 24 and interviewees went to considerable efforts to construct themselves as responsible service users.

6.2.2 Constructing a 'responsible' self

There were a number of ways in which interviewees could construct themselves as responsible users of health services, for example by offering accounts of times when they had not sought help for a symptom or when they had sought help from the 'right' service and by giving examples of the kinds of symptoms that they would not seek help for. Another way was by distinguishing themselves or their peer group – '*the likes ae us*' – from the 'irresponsible other' as described above.

Debbie: *I think it's a big benefit having NHS 24, apart fae the morons who dinnae use it properly.*

Euan: *Nah, they take the crap.*

Debbie: *Aye, but for the likes ae us who hardly ever use it, we only ever use it if need be, then I think it's a great thing that they've created so-*

Not wanting to waste anyone's time was a recurring theme in people's accounts of their decision-making when dealing with symptoms and it was mentioned by almost all interviewees. It was evident from most accounts of calling NHS 24 that people didn't decide to call without at least some consideration of whether or not it was the right thing to do.

Maggie: *I mean I, I felt bad contactin' them, and I did say this, eh the first person, the initial person I spoke to when I called, she was very ahm, I said you know 'I feel really silly phoning you, I've got cut heels from silly shoes', eh, and you know I explained that it wasn't an emergency and I didn't feel dizzy and, she asked all these questions, to obviously address the fact that it wasn't an emergency, I was just lookin' for advice. Um, and eh, and they said at that point, because it's not an emergency we'll get back to you within a, a specified time-frame, I think was it between 1 and 2 hours, 1 and 3 hours I can't exactly remember, eh, and I actually hoped it would be towards the end of that because I know the service is important for people who actually are having an emergency so, I felt that eh, on one hand I didn't want to be taking up their time, but on the other hand it was just good to get some, a bit of advice. Ehm, and, I wasn't bothered that the call-back, might take a while before they called back.*

As Maggie's comment illustrates, part of constructing oneself as a responsible user of health services is showing awareness of the potentially greater need of others and this featured in a number of accounts.

A further important way for interviewees to construct themselves as responsible was to show awareness of the cost of resources, with several people mentioning the time and budgetary pressures faced by GPs and the NHS. Jim felt that this awareness of the cost of resources is altering how people use health services:

Jim: *I think, everybody's aware, well, I think, everybody's aware of the time constraints with the doctor and, you know, the budgetary problems they've got, you know, in the health service. Well, I am anyway aware of, whereas my parents, you know, it would seem to me, I mean would just lift the phone and the doctor would come out, you know, for the flu and, you know, things like that they'd automatically get the doctor out, whereas now you wouldn't do that. Probably 2 reasons. Probably one, that... that's a thing of the past just phoning the doctor because you don't do that now you have to try and get to the health centre and maybe because, ehm, folk are, you know, there's more knowledge maybe of viral stuff that you just have to basically take aspirin or whatever and just get on with it, paracetamol, whereas on those occasions in my younger day we would have had the doctor out.*

Interviewees displayed a high level of awareness of issues of resource pressure.

However, some people felt that calling NHS 24 is less resource intensive than using other health services.

Maggie: *I think it is perhaps because you hear so much about using services inappropriately you know and people phone ambulances because they've-somethin' really trivial and you just think that's, you know it's a terrible waste of money, um, and I think anybody who's... I mean I think the vast majority of people would think that that was, that was a terrible use- I guess when you're speakin' to someone on the phone you're not lookin' at the cost of that call, and I know that, you know, so it costs to run the phone line, it costs for 2 separate people that I spoke to, it also costs for them to then process the information and log everything, um so... I, I know that there is a cost but it's maybe you don't see that the same way that an ambulance coming up you see. Ahm, I guess it's the lesser cost so, there's that kind of, you know, it's less inappropriate than phonin' an ambulance for somethin' trivial, but yeah, I, I think maybe with NHS 24 people don't realise the cost that is involved, cos it's just, if you think of it like phonin' your mum, you know [laughs], you know except she's got a medical dictionary beside her. Um, so I guess maybe that there is, people don't see the hidden cost of, of NHS 24 and that perhaps doesn't... I think maybe you don't then see the*

value if you don't know the cost you don't understand the value. Whereas with things like A&E and ambulances, when used inappropriately particularly you know that there's been a, a large cost and that could endanger someone else's life. I guess at least with NHS 24 you don't feel like someone's life is necessarily endangered, well you hope, while you're on the phone to them...

Natalie had described an occasion when she had called NHS 24 with a question but had been unhappy with the answer given by the nurse she spoke to, so she had called again to speak to someone else. However, in retrospect, she worried that this had been wasteful.

Natalie: *And I, phoned them up again with the, the pregnancy issue. Because as I say the first time- See when it comes to saying this I feel truly awful. It just seems really such a waste of resourcing. But yeah, I did phone up again when I didn't get the answers I wanted [laughs].*

However, when I asked Natalie to say more about this comment that her call seems like a waste of resources, she also expressed the view that NHS 24 is probably less resource intensive than other routes to care.

ED: *[...] do you feel a pressure when using health services to use them in a specific way? Ehm, are you quite aware of resource use and what might be appropriate or not?*

Natalie: *Ehm, I think so. Well actually yeah, ehm, I wouldn't... I would always factor in... Is this a good use of resources? Am I wasting their time? Because, well, I think everyone knows the NHS is underfunded as it were, you know, and there is such a pressure on resources and... I don't- I kind of feel that, I know this is really probably unfair on NHS 24, but that it takes less resourcing to manage a patient-adviser interaction than it does to organise keeping appointments, calling a person through, 5 minutes to remember who your patient is, 5 minutes to listen to them whinge at you, and then 5 minutes of like actually telling them they're ok [laughs] before, you know and then being late. Ehm... I feel, whereas on the phone it's a lot more efficient, it gets dealt with and it's, then the problem's gone away. Ahm, and that just seems a lot, a much better use of resources... I mean for all I know it might be a hell of a lot more effort to maintain NHS 24 than I think it is, but...*

Even those who expressed quite consumerist attitudes to the use of health services were still careful to emphasise that they are responsible in their use. While Robert has 'no qualms' about going to the GP because 'that's what they're there for', he would still go only if he thought it was necessary.

ED: *Do you tend to be quite good at looking after yourself do you think? Would you have medicines in the house that you'd take if you were feeling under the weather, or would you go to the doctor straight away?*

Robert: *Aye. Well no, I'd generally go to the doctor. I mean that's what they're there for.*

ED: *Right.*

Robert: *Aye. I have no qualms about nippin' up to the doctor for anything that's eh, medical.*

ED: *And do you go quite often?*

Robert: *No, just... ehm, no, not that often at all. I have been this last 3 or 4 weeks, these tests and whatnot, but generally wouldn't, don't go near them unless it's necessary.*

Similarly, while James used the most consumerist rhetoric of any of the interviewees, he was still careful to construct his use as responsible.

James: *Aye, I would probably say it is, I would probably say... well I can only go like, I mean when I was growin' up and if you were ill durin' the night and it was like, you had to get the doctor out it was like... y- you didnae really want to get the doctor out but... it, it's like, it was like a last resort, like unless you really had to phone the doctor you would try to, try everythin' like to avoid phonin' him eh? But like I say I think things are changin' I think... NHS 24's, the way I see it is, I mean, it's there for a reason it's there in the name suggests that it's NHS 24 eh? Eh, also you have the Accident and Emergency at the General and like, as long as you get transport there, I certainly, I understand you can wait up to 4 hours but I certainly wouldnae be afraid to use it like. As far as I'm concerned that's what it's there for eh? Eh, and I do understand the, obviously emergencies are more important but like... and I don't mean I'd use it at will like I mean I wouldnae go for a cut finger or somethin' but I mean, like I say somethin', if I was in severe pain wi somethin' I would certainly use it.*

I asked interviewees if they were aware of campaigns designed to educate people about the appropriate use of health services. Most were unaware of any campaigns but felt that they would know the right service to contact in any given situation. They thought that this knowledge came more from 'common sense' and experience, or from hearing about other people's experiences either in person or on television, than from information campaigns or official sources. Angela was the only person who actually remembered seeing an information leaflet of this sort but said that it hadn't had any impact on her behaviour because, as a nurse, she already knows what to do.

Angela: *I did, I – there was a leaflet that came in, I'd say 2 years ago now and it was eh, it's a shame cos most people would have binned it, wouldn't really have looked at it, just a little leaflet and it was just saying you know if, you know if you've got like colds and it kind of listed different symptoms, then you know just see a pharmacist or you know, somethin more serious then see the GP and, I don't remem- it didn't mention NHS 24, though, ehm, as far as I can remember, but it was just kind of, different kind of symptoms over, it was going in to winter, and who to see. Ahm, oh no! NHS 24, it must have been on there, cos there was quite a number of services listed in this leaflet and ehm, just making people aware, where they should be going with their different needs. Ehm, yeah, NHS 24 was on the leaflet. So, but people- yeah, I just wonder whether, yeah I don't know how you get the message to, across to people.*

ED: *Did that sort of thing have any impact on you, do you think? On how you behave?*

Angela: *Eh, no not personally but I think it'd be really helpful- I think just cos I'm a nurse it d- I kinda know where to go, what to do for- you know I can kind of see how serious something is and know what to do, ehm, take the appropriate action, but for ehm, the next person out there I think it'd be really helpful for them to understand, ehm, but the information on the little leaflet's not super.*

However, as discussed in Chapter 4, the 'right' thing to do in any situation is contingent on situational and attitudinal factors. This was illustrated again by a comment made by Lauren when we discussed the idea that it might be easier to call NHS 24 out-of-hours than to take time off for a GP appointment during the day. Her initial response was that this would be 'silly'.

Lauren: *Yeah. I- I wouldn't do that. But maybe that's just like, different opinion on what's sensible. But I would just, I mean if you've got to take time off work to go to the GP, you've got to take off time, like going to an out-of-hours GP, just cos that suits you more, I don't really think that's a very good approach to the NHS. That's just like, you being busy. I wouldn't do that. Unless I absolutely had to. But I think, I think for me anyway, the only time I'd call NHS 24 is when something got suddenly worse at a time there was nothing else I could do.*

By qualifying her statement that she 'wouldn't do that' by adding 'unless I absolutely had to', Lauren shows a recognition that what people are willing to do and to justify as reasonable or responsible is determined by the situation they find themselves in.

Breaking the rules

Some people talked about times when they themselves had felt criticised for not using health services appropriately. Alison told me about a time that she had gone to A&E with bleeding which she described as *'frightening'* but had been told by a doctor that she shouldn't have just shown up without being told to go there. This experience had clearly upset her and she said that she wouldn't do it again. Andrea said that she thinks it can be a problem *'when you're not following the rules'* but she said that when she is very unwell she is *'just looking for help basically as quickly as possible'*. She sees going through the process of calling NHS 24 in these circumstances as prolonging the wait to get seen.

Grace said that her husband had a similar attitude to Andrea. When she had earache he had wanted to take her to A&E, which she said is *'always his answer'*, but she persuaded him that it is not the *'right'* thing to do.

Grace: *[...] he's always the one 'take them to A&E' and I said 'No! That's not the way you do it! You have to phone NHS 24 first', so eventually he phoned NHS 24*

Grace said that she talked him out of just going to A&E because she *'knows the procedure'* and, as a result, when he recently experienced chest pain he called NHS 24. Grace saw this as evidence that her husband has learned the right thing to do.

Grace: *Oh I think A&E's, I always think of A&E as, you've been in a car accident and you're bleeding and it's really, really bad or, an elderly person's fallen and hit their head and, that's what I think A&E is, it's gotta be really bad. I wouldn't, I wouldn't go to A&E. I'd be frightened to go to A&E! But ehm, no I'd phone NHS 24. But I think my husband is, wants to go to A&E, to cut out time wasting, because he can drive and take me. But, ehm, it's not always the right way to do it. You've gotta follow procedure. And he does it now [calls NHS 24]; he did it the other day. It worked for him, so maybe he'll be different now.*

Because John takes anticoagulant medication he has been told that he should seek help any time he starts to bleed. He usually calls NHS 24, but when he can't get an immediate response from NHS 24 he will contact his local A&E department. His comment that he is sometimes told by a nurse to *'stop annoying her'* suggests that he has previously been reprimanded for calling.

John: *I can get, phone up NHS 24. If they're busy, and I need a doctor or advice in a rush, I'll just phone up [hospital] and ask for A&E, the staff nurse at A&E, get her on the phone and say listen, I need-, explain to her ma circumstances and all that and what's happenin', and 9 times outta 10 she'll tell me either to bugger off and stop annoyin' her, or phone for a doctor.*

John also said that he has been told by his GP to stop phoning 'every time he sneezes', but he rationalises his behaviour by saying 'well, I sneeze, there's usually blood comin' out at the same time'. While he is aware that his repeated contact is viewed as problematic, he is also confident that he is doing what he is supposed to do and mitigating risk by seeking help.

These accounts illustrate the tension between wanting to do the right thing and wanting to access help as quickly as possible and show that while people may be aware of 'the rules' they do not always find them easy to follow.

6.2.3 Taking responsibility by seeking help

The lack of clarity about what it means to 'take responsibility' means that it can be interpreted in various ways. When people criticised the 'nanny state', they implied that taking responsibility means greater use of self-care and making decisions without recourse to professional advice. On the other hand, many of the accounts presented in this research suggest that 'taking responsibility' can be understood as not taking unnecessary risks and seeking help if uncertain or worried about a symptom. For example, while Jodie has strong views on self-reliance and individual responsibility for health, when I suggested to her that calling NHS 24 when her daughter was injured could also be seen as responsible, she was quick to agree.

Jodie: *Ehm, so I think in terms of taking responsibility, I think, I think yes. Especially when you're caring for somebody else you have a responsibility to use expert advice where it's- where you should and where you feel is appropriate. Ehm, I think once things have been ruled out and there's still an issue then that's where people need to take on responsibility themselves, ehm, to change things.*

Maggie, in particular, was very reflexive about why she tends to be cautious and doesn't like to take chances. She explained her attitude in the context of her personal

history, and suggested that being prepared is a way of taking responsibility, it is something which you ‘owe to yourself’ and to others.

Maggie: *I don’t know if it’s, [sighs] I think, I probably tend to look at what the worst case scenario might be, often, I mean it’s the same just in anything in life, I always think first what’s the worst that could happen and be prepared for that. And then, if it does happen I’m prepared for it, and it’s probably unlikely to happen, but at least I know the kind of degrees of what might happen on the way there. So I’m always... not, I don’t think I’m a pessimist, really, ehm, but I just like to be prepared, I like to, to be forearmed, I don’t like things to come as a surprise. And I think especially with health, things, ehm, a f- oh, well years ago actually when I was sort of going through the process of becoming divorced, ehm, I went through quite a heavy drinking phase and my health wasn’t, it’s not my health wasn’t good, my health was remarkably robust actually given what I put myself through, um but I had a few accidents, falling over and things, and being stuck with no battery in your phone, in [city], in you know a, a boyfriend’s house, ehm havin’ hit your head from goin’ to be sick, something that, I think, I think those things have made me much more cautious, you know when I calmed down and realised what was happening, all of those things, ehm, sort of bein’ stranded and not knowin’ what to do and, that’s why I like to be prepared. So now I’m, I’m probably over-compensating for that, for my reckless behaviour in my late 20s [laughs]. Be prepared, yes.*

ED: *Well that’s a good sort of, philosophy I suppose.*

Maggie: *It was, it was a hard lesson to learn to be honest, but you know, I think there’s that kind of thing you owe it to yourself but you owe it to other people to know what to do if somethin’ happens as well so...*

Heather’s attitude that NHS 24 is a service she can contact in order for someone else to make a decision about the best course of action could be interpreted as an abdication of responsibility.

Heather: *Ehm, it’s, it’s a place to start I think, for me. Yeah. A place to start. Because, I’m only callin’ them if I don’t know which way to take it, you know, is it a doctor situation or is it a hospital? So that’s why I would get them to kinda decide for me. Yeah.*

However, in a situation where she doesn’t feel she has adequate knowledge to make a decision by herself, this could also be seen as a responsible approach. In her research with mothers who had called NHS 24, Ireland (2012) found that mothers felt a responsibility to look after their children themselves and drew on their knowledge of their children when making decisions (see also Houston and Pickering

2000). However, because this knowledge was usually of their children while *well*, illness fell outside the realm of their expertise. Therefore, although they felt a strong sense of responsibility for their children, illness created a need to share responsibility with someone who had more expertise.

Chapter 5 highlighted the sense of risk experienced by people when making decisions about symptoms and the idea that not seeking professional advice can put oneself or others in unnecessary danger. This was noted by Julie and Steven who thought that their own reluctance to seek help was typical of their rural farming community. Although their examples are quite exaggerated, they highlight an awareness of the risks involved in not seeking help in time.

Julie: *And again there's a lot of farmin' up here, like, you ken what farmers are like tae, they'll just no go, him tae, he'll just no go-*

Steven: *Just keep going!*

Julie: *- they'll wait until their limbs are fallin' aff, you know, before they go, and sometimes it's too late.*

ED: *And why is that? What would stop you from phoning up?*

Steven: *Cos you think you'll get better. You know it's just a pain, or you've hurt yourself or you've lifted something wrong or, banged yoursel', it's your own fault, it'll get better.*

Julie: *You hear it aw the time.*

Steven: *Sometimes it does, sometimes it doesn't.*

Julie: *And then you hear the next week they're no there cos they're deid. And you think woah, woah, you know.*

Steven: *Shoulda gone to the doctor's sooner.*

Julie and Steven acknowledge that waiting until symptoms become serious before seeking help can lead to worse outcomes and Julie described this as '*not the way to go either*'. There is clearly a fine line which must be negotiated between being responsible and being irresponsible when it comes to making decisions about health and help-seeking.

6.3 Summary

It is well known that the majority of symptoms are managed in the popular sector and that people regularly care for themselves and others without seeking professional

advice (Hannay 1979; Elliot et al. 2011; MacKichan et al. 2011). Most of the participants in this study indicated that self-care is part of their usual response to symptoms and most had attempted some form of self-care for themselves or their children before their most recent call to NHS 24. However, for some people, concerns about medication or lack of confidence in self-prescribing meant that they felt a need to seek advice before taking anything.

For most interviewees, it was reported as usual to ‘just suffer’ or ‘just get on with it’ when they are ill and seeking help is not the first course of action. The inconvenience of finding time to see a GP and difficulty in accessing appointments in many areas mean that people say they will only consult if it is ‘really necessary’. However, the length of time people are willing to delay help-seeking depends on the symptoms and for some things, such as Lauren’s impetigo, a consultation will be made immediately. People are also less willing to wait when children or adults they care for are ill. This is linked to the idea that children are at particular risk and can deteriorate quickly.

As might be expected given the range of understandings of NHS 24 expressed in chapter 4, there was also a range of different attitudes to using NHS 24 as a way to manage lack of access to other services. For some people, such as Maggie and Natalie, NHS 24 is seen as more available and less resource-intensive than a GP appointment and so they describe themselves as more willing to use it than the GP. However, for others it is seen as for urgent or emergency care and so they reported that they would prefer to wait and make a GP appointment, only turning to NHS 24 if they needed immediate help when the GP was unavailable or if they couldn’t access an appointment, for example because they were away from home.

It was important for participants in this study to be seen to be responsible users of health services and not to be considered ‘hypochondriacs’ or ‘time-wasters’. However, as Goode et al. (2004a: 229) note, there is no accepted definition of what responsible or ‘appropriate’ demand means in the context of NHS Direct or NHS 24. Interviewees’ views of what constitutes appropriate health service use drew largely on examples of what they considered to be misuse of emergency departments and ambulance services and many were clearly influenced by media reports. As in other

studies (Goode et al. 2004a; Cross et al. 2005; Richards et al. 2007; Adamson et al. 2009), people did not consider that their own use of services was inappropriate although in some cases they acknowledged that, in retrospect, their symptoms may not have been clinically serious. People were also largely unwilling to engage in discussion about what is or is not appropriate use of health services but, when prompted, they focussed on social rather than symptomatic factors in their constructions of deservingness, in a similar way to health service staff (Jeffery 1979; Smith et al. 2001; Cross et al. 2005).

As discussed in chapter 2, self-care and help-seeking are inextricably linked with issues of morality and responsibility. However, what it means to be responsible is contingent and contextually defined. While people used accounts of times that they had cared for themselves or others without seeking help as a way to construct themselves as self-sufficient and responsible, they also used accounts of seeking help, when it was ‘the right thing to do’, to demonstrate responsibility. As noted by Pill and Stott (1982), definitions of responsible behaviour are correlated with beliefs about illness causation and the extent to which someone can be considered to be morally accountable for their illness. Therefore Natalie didn’t call an ambulance for her unconscious husband who had been drinking and noted that when she attended A&E with a friend who fell off a swing, they were both sober.

Importantly, Pill and Stott (1982) also found that one of the reasons that people could be blamed for their illness was if they didn’t go to the doctor or delayed for too long before seeking help. If people choose to ignore worrying symptoms they may place themselves or their children in danger of more serious illness which could have a cost to both themselves and to others. It was clear from the accounts presented here that there are situations in which seeking help is seen as the most responsible course of action but this may conflict with the imperative to use health services responsibly and particularly with messages not to consult about minor illnesses. People must therefore negotiate complex discourses about what it means to be both a responsible citizen and a responsible patient or parent when making decisions about symptoms. For some people, calling NHS 24 is a way to share the burden of responsibility but for others decisions about calling NHS 24 also invoke anxieties about help-seeking.

7. Lay and professional knowledge

Throughout this research, participants drew on discourses of social and demographic change to explain increased demand for and reliance on health services. The assumption expressed is that a decline in close kinship networks and social support means that people have less access to the experiential and folk knowledge which was used to deal with episodes of minor illness in the past. While it is true that family types and the dynamics of care have changed over the course of the last 30-40 years (Williams 2004), the assumption that this inevitably results in a loss of commitment or closeness has been questioned (Mason 1999; Williams 2004) and research on household change suggests that ‘families still matter’ (McRae 1999). At the beginning of this chapter, I show how these assumptions about social change were present in the accounts of participants (though mostly in focus groups rather than individual interviews). I then outline the households and families that interviewees described being a part of and show that most people interviewed for this study were embedded in close family networks, while those who lived some distance from family described using communication technology to remain in regular contact. Most of the accounts do not suggest social isolation or a lack of support from family or the wider community, although a small number do.

As discussed in chapter 2, the reported weakening of the popular sector of health care has also been linked to processes of medicalisation (Illich 1976; Kleinman 1985; Conrad 2007), though it has been argued that greater access to education and information has led to ‘lay re-skilling’ as people re-appropriate ‘expertise’ (Giddens 1991; Williams and Calnan 1996a). Certainly, a key factor which affects decisions to consult about minor ailments is knowledge or lack of knowledge about symptoms and treatment (Cantrill et al. 2006) and in this chapter I consider the types of knowledge that interviewees say they seek and draw on in their interpretation of symptoms and in deciding what to do about them. The accounts given suggest that people access knowledge about health and illness from a variety of both lay and professional sources; however, with some notable exceptions, the majority of interviewees expressed a lack of trust in lay knowledge.

While lay consultation and information seeking continue to be part of people's decision-making, in the episodes which led to interviewees' most recent calls to NHS 24 this was often simultaneous with formal help-seeking and sometimes seemed to be more about obtaining affirmation or reassurance than actual advice. Many interviewees spoke about the decision to call NHS 24 being due to a desire to speak to a 'professional' or an 'expert' and the final section of this chapter explores the emphasis that seemed to be placed on the limitations of lay knowledge, which many interviewees constructed as inadequate or inferior to professional knowledge.

7.1 Family networks and support

During my observational fieldwork and in the focus groups with NHS 24 staff and with members of the Patient Participation Forum and Clinical Governance Public Panel, people frequently drew on a discourse of social and demographic change to explain increased reliance on formal health services. This is what Mason (1999: 156-7) refers to as a 'geographical discourse about the morality of kinship' which 'invokes ideas about what distance does to the operation of kin relationships' and is also 'a vocabulary about how kin relationships should work, or about what is good or bad in them'. The assumption expressed in the focus groups is that, in contrast to the past when people lived in communities and '*families had grannies*' living in the next street, community is now '*fallin doon*' and people, especially young parents, are more isolated. This argument, which I heard repeatedly, is summarised in the below comment from Hazel.

Hazel [PPF member and nurse]: *I think there is a generational thing in it because families are more diverse now and you- families had grannies, eh, and they were quite close and you know granny's word was law and big families they all knew how to deal with things because they'd went through it a hundred times you know, you've got half a dozen kids, you go through the temperatures, you go through the, the crying stage, you know what's-. But now people are so far away from their families, a baby cries for 2 hours there's obviously got to be somethin' wrong. They've got no structure round about them to tell them that this is normal. You know, they might be cryin' for nothin', you know. Eh, and the- they just, people then seek help, and I think, from my point of view we get a lot of calls like that, basically because people don't have the structure to say, to give them the support to sorta tell them 'This is how you cope with this', you know? There's as I say children are great things cos they don't come with a book, and not everybody's you know,*

there's not a set way of bringin' a child up. There's not a set way how an illness goes either, and everybody's different. So, but if you haven't got that support network round about you you've got to look somewhere else and I think that's what a lot of people do and because people have to be- move out of the areas and families are not closely knit together anymore then your- that support network's gone. The advice is gone as well. They've got to look at other places for the advice.

This idea that people are more socially isolated now than in the past also emerged in a small number of the interviews, where it was usually mentioned in relation to young mothers and in one case to older people living alone. For example, Angela, who works as a health visitor, talked about the stresses faced by mothers whose partners were working away from home and Paula described being told by a nurse that young mothers who had moved to her area were 'quite needy'.

Paula: *I think with people moving, you know and like, the, the nurse was saying to me that ehm, lots of families come from abroad you know to, to get jobs in [nearest city] and then they move out here cos it's cheaper and, you know and, that they've got no friends or relatives and, ehm, so I think that, in that way, they would need to use [health services], cos where else would they go, you know really? And I think they should be able to, you know, for, for care of them so.*

Paula thought it would be 'scary' to have a small child and not to have family close by to help out. Angela, Jim and Laura all described having met parents who were bringing up small children without family support, in contrast to their own family situations, and they thought that these other families would rely on health services more than they would themselves.

Laura: *And I suppose we're quite lucky that oor parents are still relatively close, not on the same street but, you know I have lots of friends who have moved to the area who have no family no-, you know, no support structure, ehm so I do think about it, all of those things a lot.*

The idea that people rely on health services due to a lack of family support was not raised in the focus groups with mothers of young children and with older women and when it was mentioned in individual interviews it was almost always in relation to others. For the small number of interviewees who did mention feeling a lack of support themselves, it was not directly linked to whether or not they had family

nearby. In fact, most of the people who explicitly talked about feeling unsupported were carers of other adults, and they were usually talking about a lack of support from health and social services, rather than from family or community.

Many of the interviewees did have family living nearby, although there were numerous stories of dispersed kinship networks, where parts of families were nearby but other parts were quite distant. This was often due to separation, divorce and emigration, leading to non-nuclear family types. Some of the interviewees had themselves experienced divorce and some had children with former partners or current partners; for others, their own parents had divorced and they had step-parents and step-siblings.

Of the people I interviewed, only John and Maggie live alone. John had lived with his mother until she passed away the previous year. He doesn't currently work and he gave the impression that most of his interactions are with health and social care workers. He has a brother and a sister who both live some distance away but who call him every couple of weeks. Maggie is divorced and lives alone, though she has a partner and also keeps in close contact with her parents and brother by phone. The only other person not to live with family is Lauren, who lives in a shared student flat with 4 other girls and has a sister living nearby.

Tracey and Andy, both in their early twenties, live at home with their parents. Alison, Nancy and Josie are all single but have their grown-up children living with them; both Nancy and Josie are carers for their adult sons. Matthew, Irene and Natalie are all childless and live with their partners. Jim, Tina, Doreen, James and Robert live with their partners and have grown-up children who have left home. Paula lives with her husband and has grown-up children who have left home, as well as one teenage son still at home. The other 13 interviewees live with their partners and have young children. Of these 13 families, in 5 cases members of the extended family were providing formal support for childcare and in 2 more cases grandparents helped out occasionally. Of the 8 participants with grandchildren, 6 reported being involved with their grandchildren and offering occasional childcare.

When the issue of dispersed families was raised in the focus group with members of the NHS 24 PPF, most people in the group seemed to accept the idea that geographical distance leads to a lack of support. However, Elisabeth challenged the consensus by suggesting that technology can counteract the effects of distance and that lay consultations are no less likely in dispersed families.

Angus [CGPP FG]: *That, the point is in the modern gener- the modern li- the way we live now, they don't have that, tend not to have the same close relationship-*

Bruce: *Correct.*

Elisabeth: *No, no.*

Angus: *-they're not living in the next street.*

Elisabeth: *That's right aye, but, there, but the point I... in general, communication is better because mobile phones etcetera so that even if somebody's living 200 miles away, 400 miles away they can phone mum and say 'The bairn's doing this n that what do you think it is' or 'I've got this and what do you think it could be' and even then, even at that distance they'll take the prompt then, och phone NHS 24 or .com whatever, you know...*

Indeed, most of the interviewees who had family members living elsewhere described using the telephone and internet to remain in regular contact. This is important as it demonstrates that more dispersed family networks do not necessarily lead to a lack of closeness but just to new forms of 'mediated closeness' (Kirk et al. 2010). For example, Maggie and Claire both talked about phoning their mothers regularly, Tina uses Skype to keep in touch with her sons and grandchildren who live in another county and Tomasz and Irena use Skype to speak to family and friends in Poland.

Overall, the situations of the participants in this study do fit to some extent with the picture of dispersed families presented in the focus groups and there were some cases where distance may mean that people don't rely on family support to the extent that they might otherwise. For example, although Irena keeps in touch with family in Poland via Skype, she did say that she doesn't call her mother for advice about her baby because she's so far away but that she would probably have been her first point of contact if she was '*living in the next village*'. However, and importantly, it would be inaccurate to say that geographical distance from family necessarily leads to

social isolation and a lack of lay support or even to assume that kinship networks are the most important factor influencing help-seeking behaviour at all. As the following sections will show, many interviewees do draw on their social networks and engage in lay consultations but they also incorporate other forms of knowledge into their decision-making and even where lay knowledge is accessible it may not be perceived as legitimate.

7.2 Lay knowledge

In making decisions about symptoms, I found that people draw on a variety of types of knowledge from a range of sources. As well as knowledge gained directly from expert sources, most usually health professionals (but sometimes from books, television or the internet) this includes their own experiential (Borkman 1976) or embodied knowledge as well as socially derived knowledge (Schutz 1946) based on the experiences of others. It also includes a sort of instinctive knowledge, or ‘common sense’, akin to Schutz’s (1946) ‘things taken for granted’ which involves ‘*just knowing*’ what to do in a given situation. Pols (2012) describes these different types of knowledge as actual ‘knowledge’, which is concerned with facts; ‘know-how’ which includes embodied and experiential knowledge; and what she terms ‘know-now’, or knowing what to do in a specific and immediate situation. All of these types of knowledge are to some extent present in the accounts presented here and generally people constructed themselves as having knowledge and being competent and confident in using it to care for themselves and others on a day-to-day basis. However, many people were careful to point out the limits to their own knowledge and the dangers inherent in relying on their own interpretation of symptoms rather than seeking professional advice, particularly if symptoms were unfamiliar or potentially serious.

7.2.1 Knowing from experience

The concept of experiential knowledge can be defined as ‘truth learned from personal experience with a phenomenon’ (Borkman 1976: 446), and the importance of this knowledge was clear in people’s expressed confidence in dealing with illnesses themselves if the symptoms are something they have dealt with in the past

or experience on an ongoing basis. Interviewees were able to give numerous examples of symptoms for which they wouldn't seek help out-of-hours, such as Debbie's sciatica or Matthew's occasional back pain following an injury. People will not seek help for such symptoms, even when they are in pain, because they know the cause of the pain and that there is nothing immediate that can be done about it. People who deal with chronic or recurrent problems come to understand how to manage their symptoms, or their children's symptoms, themselves. Almost half of the interviewees in my sample had at least one long-term condition, as described in chapter 6, and most had developed a high level of understanding about their conditions and how to manage them. For those whose call to NHS 24 was in some way related to their long-term condition, it was usually because something had worsened or changed.

Similarly for acute conditions, it was clear that people tend to seek help when a symptom is either new or particularly serious. For example, Gail made it clear that she decided to contact NHS 24 following a blow to the head because she had no way to determine what a '*normal*' concussion was like.

Gail: *Ehm, I just knew that I still didnae feel right, and I knew fine that I just didnae feel right, I felt awful, and I wasnae sure whether I had done everything that- cos I've never had a concussion before, I had no idea what, what was involved [laughs]. If that was normal, if it wasnae normal, you know?*

Heather also said that she called NHS 24 because she had no way of assessing whether or not her son's symptoms were '*normal*' as she had never had a boy before.

A number of people mentioned stomach bugs as an example of a normal illness that they know how to deal with and talked about it being something that they wouldn't seek help for unless it was particularly severe. However, '*throwing up blood*' or '*passing blood*' would lead people to seek help, or just a '*feeling that it's getting worse*'. For Paula and her husband, it was the severity of the stomach pain that caused them to call NHS 24 when they both had vomiting and diarrhoea.

People gain experiential knowledge from their interactions with health professionals. The parents I interviewed often explained how they have learned from previous consultations about children's symptoms and gained confidence in dealing with things over time. For example, Andrea talked about being terrified the first time her son had croup and needed to be taken to hospital but said that now she can recognise the symptoms and keeps medication in the house to deal with it. I asked people if they felt that the advice they had been given in their recent call to NHS 24 had increased their knowledge or confidence to deal with similar symptoms in the future. For some this was the case, and they said that they would not contact NHS 24 about the same symptom again because they would now know how to care for themselves. They also said that they knew what to look out for that might indicate worsening and that they would only call if something was different or worse. So for Gail, now that she understands the signs of concussion better, she said there would be '*no point*' in calling NHS 24 if she hit her head again in the future and felt the same.

Others said that they wouldn't phone NHS 24 again about a similar symptom because they had needed to be seen by a clinician anyway (over half the sample had some further contact with health services about the same issue), and so they would wait for a GP appointment or go straight to an emergency department in a similar situation in the future. For example, Angela had at first been given home care advice for her daughter's earache but had called NHS 24 again after 24 hours and been given an appointment. Angela said that in a similar situation again she would first follow the home care advice she had been given by NHS 24, which she thought was good, but that if things hadn't improved after 24 hours she would go straight to hospital rather than seeking assessment from NHS 24.

ED: *So if Holly or one of the other kids had similar symptoms again, what do you think you'd do?*

Angela: *Because I know there's a GP out-of-hours service, I wasn't quite sure what the set-up was, because I know the GP out-of-hours is there and they will see children, I would just go straight over to the hospital-*

ED: *Really?*

Angela: *Because they're there all night, I had a wee chat with the doctor who was there and got to understand, you know, they're there all weekend, all night, so ehm, yeah I'd just go straight over.*

When interviewees said that they would ask other people for advice about symptoms it was often because they were considered to have experiential knowledge. For instance, Claire values her mother's advice because she has brought up 5 children and now has 9 grandchildren. Likewise, Heather's mother raised 5 children and Heather turns to her for advice on that basis. Of particular note was the value placed on experiential knowledge by Debbie and Euan, who talked throughout their interview about their reliance on Debbie's mother for health advice. She is the first person they call whenever they want advice and on the occasion when they called NHS 24 it was because they hadn't been able to reach her. Again, this knowledge has been gained by bringing up children, as well as other experiences across the life-course.

ED: *And does your mum have clinical training?*

Debbie: *No. No, just years o, listenin' and-*

Euan: *Just years of experience really like, her daughters and that and-*

Debbie: *Aye, aye cos there's 4 ae us, so she brought 4 ae us up and then she brought near enough ma auntie's 3 up as well so, between all that and, years ae bein' on the buses and, she used to work for the handicabs and, aw different things so just line ae work and and aw that she's learnt a few things over the years. And, mother knows best [laughs]. You know, well maist ae the time [laughs].*

While this experiential knowledge was valued and often drawn upon in decision-making, it was (perhaps obviously) only considered suitable for the types of situations in which others could reasonably be expected to have experience. The limitations of experiential knowledge will be returned to in section 7.2.3.

7.2.2 Sources of knowledge in the popular sector

Although people talked about sharing experiences with others and sometimes asking for advice, when I asked about the sources from which they got *knowledge* or *information* about health and self-care few people actually mentioned that they learned from other lay people, referring instead to doctors, nurses, health visitors and

occasionally pharmacists. Apart from Debbie and her husband Euan, who discussed the passing on of lay knowledge in families at some length, there was very limited discussion about this, even when prompted. A small number of people mentioned that they had learned things from their mothers or grandmothers, though some people seemed to class this as ‘*common sense*’ rather than ‘*knowledge*’ and to distinguish between the two; for example Angela talked about her parents’ reliance on what she called ‘*common sense*’ rather than medical expertise in quite a critical way.

Angela: *Ehm, yeah because... because they rely more on what their parents told them, the way that they were brought up, ehm rather than the wider, taking on knowledge from other sources, it's more what their family norms were and what they think from, yeah just what's been passed down generationally to them. Ehm, whereas we've taken on board other influences eh, as credible, whereas they tend to be quite, oh I don't like to say but, a bit narrow minded, really, they kind of say 'Oh yes', it's kind of typical working class kind of chat it's just like, 'Oh yeah you know, I went to see this doctor you know and ehm, he-' yeah they... they ehm, seem to think they know better than the doctor, who's so highly educated.*

Some people were critical of the home remedies or adages of previous generations, for example, Julie referred to being given ‘*stupid sugar and whisky*’ for colds when she was younger and Grace dismissed her grandmother’s treatment for earache as an ‘*old wives tale*’.

ED: *And what sort of things would she do to look after you when you were unwell?*

Grace: *So... Lucozade! [Laughs] Ribena, hot Ribena, ehm, comfort, keepin' you warm, attending to your needs. Ehm, if there was medication I had to take do that, when I had a lot of ear problems it'd be cotton wool with stuff in it which she used to stick in my ear. Old wives tale. Ehm, you know the, general things that nans do.*

Maggie dismissed her father’s advice to rub garlic on her sore feet because she didn’t think it was ‘*scientifically informed*’; though she keeps flat lemonade in her home because a nurse once told her that it’s a good way to replace sugar after sickness. This suggests that non-medical remedies are considered to be more legitimate when suggested by someone considered to have expertise and these comments serve to present people as sceptical of advice originating in the popular sector which may not be perceived as ‘legitimate’ compared to professional advice (Stevenson et al. 2003).

However, there were also some examples of lay remedies that people do use such as Robert's '*milk for a sore stomach*' and Tomasz's '*raspberry juice with hot tea*' for a temperature. Notably, many of the lay remedies that people described using were considered to be comforting rather than curing and would be used in addition to rather than instead of prescribed medication or over-the-counter pharmaceuticals.

Television was highlighted as a source of information about health by a number of people. It seemed to have a particular impact on views about appropriate use of health services, as described in chapter 6; however, a small number of people also felt that they gained practical knowledge about health and illness from watching TV.

Debbie: *We're quite knowledgeable, in certain medical things.*

Euan: *And to be honest, we're knowledgeable cos o the stuff we watch on telly.*

ED: *Really?*

Euan: *Aye, well there's a lot of stuff on the telly, cos you've got, eh 'Emergency 999' I mean, they'll have 'Grey's Anatomy', I ken it's nothin' to dae with it, but it's all medical, 'Casualty' and stuff like that, and it's things that do actually happen to people, like you think, 'Oh that's what it is' -*

Debbie: *That 'A&E'*

Euan: *'A&E' that's brilliant as well, on Channel 4. Ken it gies you that sort ae look at Accident and Emergency and what they're actually for.*

Debbie and Euan had examples of treatments and remedies that they had seen used on TV programmes which they felt they could put into practice, such as putting honey on a burn, or using the '*glass test*' for meningitis. Interestingly, television is not a new source of health knowledge, as demonstrated by Doreen who self-diagnosed gall stones after watching a TV programme over 30 years ago. She had been in pain for 5 years, and had been told that she had an ulcer.

Doreen: *[...] and then I found out eh, there was a film on, used to be on every week, eh 'Your Life in Their Hands', who do operations, and the gallstone operation came up and they were talking to a girl that had the operation and she was telling the symptoms and then you seen the operation getting done and I says to- I says, 'That's what I've got'. So, eh, I went to the doctor and I says, eh, [laugh], I felt that stupid, I was frightened to say you know self-med-, self- you know, telling myself what I've got. I says, 'I've seen a- watching the television last night and I seen the 'Your Life in Their Hands',*

and this girl had gallstones and she had the operation and she's alright', I says, 'the symptoms I've got, the pains I get right round, you know, are tight gripping', I says, 'the very same pains I get'. He says, 'Oh, well, I'll send you up to the hospital, get an appointment for you', and they sent out a sachet of this stuff I had to drink, went in, and they just found them and I had the operation.

Doreen's account of being able to challenge a misdiagnosis based on information gained through television is an example of the way in which the media can 'contribute to the growth of a critically informed lay populace' (Williams & Calnan 1996: 1617) and allow people to reinterpret their embodied knowledge in light of new information. However, there was still a notable wariness of self-diagnosis in many of the accounts and the idea that this information can be 'dangerous' will be explored further below.

Use of the internet

The internet was described as a source of knowledge about health and illness for about half of the participants in this sample, although it is only an important source for a very small number. The internet is not used at all by at least 4 interviewees, and is used only in a very limited way by at least 6 more, which is not surprising given that almost a quarter of households in Scotland have no internet access (Ofcom 2013). There was also some evidence of the 'digital divide' (RSE 2014) in this sample as those with limited or no internet access generally tended to be older and of lower socio-economic status; although Matthew, the oldest interviewee at 75 and an internet user, was an exception to this.

Of those who do look for health information online, the most common approach is to enter symptoms into a search engine such as Google. Some people specified that they would then select what they considered to be reliable websites from the search results; usually NHS branded sites or well-known sites such as Netdoctor, Netmums or Babycentre. It is important to note that, when talking about using the internet, people were frequently unsure about what sites they had used. Just under half said that they had ever looked at an NHS 24 website, although some people were not clear about whether they had or not. Some people knew they had seen an 'NHS' website but were unable to recall if it was NHS Inform, NHS24.com, NHS Choices

or something else. Of those who were sure they had used an NHS 24 site some found it helpful, although Claire said that she finds it *'hard to navigate around'* and Irene said she doesn't find the A-Z very good because it's hard to find exactly what you're looking for.

The other sites that people use include internet forums where people share experiences of symptoms and illnesses. Maggie, Katie, Heather, Grace and Natalie all discussed using internet forums but said that they don't leave comments, they just look to see what other people have said. Maggie described these sites as *'the silly ones'* and said that she wouldn't trust them and Natalie said that she thinks looking at forums can be a *'bad route to take'* because people are usually describing worst case scenarios. Heather and Katie both use Netmums and Katie said she likes it because *'it's just nice to know that other people are experiencing the same thing as you as well'*. Similarly, Grace looks on forums to see the experiences of other young people with arthritis, which she finds reassuring.

Grace: *That... the doctors haven't been able to help them, they feel frustrated... Ehm, they feel bad at certain times and they need help, and it's not there. And it's nice to know that you're not the only one. Cos when you are young and you suffer from something that, you go to the hospital and you sit in the waiting room full of old people, I've got nothing against old people but you're like, I don't, I don't, I can't relate to this. You know, so, it's nice to know that there are other people my age, which is sad in a way, but there are other people my age and even younger.*

A number of people had looked for information or advice online before their most recent call to NHS 24. Maggie had looked on the NHS 24 and NHS Choices websites but had been unable to find the information she wanted. Tina had Googled, and had looked at Wikipedia and an American website, but didn't find any information that she felt she could trust. Heather had Googled and found information which increased her worry, because it suggested that her son's symptoms could be a sign of something quite serious. Lauren's friend had put her symptoms into the symptom checker on NHS 24.com, but when the outcome suggested that they should call 999 Lauren thought that might be *'a bit severe'* and decided to call NHS 24 instead. Andy had Googled his symptoms and had found self-care advice on an NHS 24 website which he had been following but his symptoms weren't improving. Angela

had also looked online but said that the advice on the NHS website she looked at was different from the advice she was given when she then called NHS 24.

Some people, such as Natalie and Heather, had looked online but couldn't find information that was relevant to their particular situation. They didn't feel confident that they could match what they were reading closely enough to the particular symptoms they were worried about. This was mentioned by others as a reason for not always finding online information useful and Irene suggested that this lack of personalisation is a flaw in the model of online information.

Irene: *You know, it's- it's a kind of, I think it's, it's hard to do something like that online, which is why the NH helpline's good, because you, you know, you get much clearer advice from people who have had more experience, it's not a kind of, you know, a kind of, diagram of, you know, follow gates that you've to go through.*

ED: *Yeah.*

Irene: *You know. I think- I think that's what I've found. You know, you think, well it's not quite that, but they're not ask- I think what I've found with the, the help- the online is, ehm, it's not quite asking the questions that you want it to ask, whereas you can say to somebody, well this is really what's happening.*

Almost everyone who said that they look for health advice on the internet also said that they wouldn't trust the information that they find online. They were careful to construct themselves as responsible consumers of information and usually emphasised that '*sifting through the rubbish*' requires some level of skill. However, as Nettleton et al. (2005: 983) have pointed out, when people say that they don't trust online information it may not 'reveal any underlying truth' but rather is an example of how people construct themselves as 'careful', 'discriminating' and 'sensible'.

Some people said they would be most likely to trust advice or information that tallies with what they already know. For example, Andy trusted the advice he found online because the symptoms described matched closely with what he was experiencing. A number of people also said that they always look at more than one website, as a way of fact-checking or cross-referencing information. For others, it was important in

constructing themselves as responsible to show that they would not use online health information at all.

Andrea: *I've got a friend that self-diagnoses herself all the time, ehm, and I never go onto the computer.*

ED: *Really?*

Andrea: *Oh, I would never, ever do that, ehm, I think it can multiply and grow, ehm, and, no, I would never self-diagnose.*

Lauren: *I have no idea where she typed that in to. Might have been an NHS thing I don't know. Ehm, but I certainly would never have done that, I would've been like, just find the number for NHS 24, and we'll phone them.*

For most people who don't use the internet to find health information, the primary reason is that they don't have internet access or are not comfortable using the internet. Others stated that they prefer to speak to someone in person when they want health advice. Reasons for this included a general mistrust of technology, the need for personalised information, a desire to speak to a 'professional', or a sense that looking for information online increases anxiety unnecessarily. Matthew told an anecdote about a friend who had demonstrated the dangers of looking up symptoms online to explain why he didn't think it was a good idea.

Matthew: *One evening, just for fun, he looked up on the internet, he thought of all the symptoms he could think about himself, and looked up and then wrote a list of all the illnesses he'd got. And he said 'That's really amazing, I should be dead! I feel much better after that!' [laughs] I mean he did it as a joke, but what he was illustrating in the conversation was the dangers of lay people looking things up on the internet.*

The language of 'danger' used by Matthew was also used by others. Irene said that '*too much knowledge can be a dangerous thing*', while Doreen said that '*a little knowledge is dangerous*'. Tracey said that she avoids looking health-related information up on the internet because '*too much information*' can be worrying, and James expressed similar views.

James: *I mean I, I know when I was younger ma mum had a, she's probably still got it it's like a big dictionary ae illnesses and she would try to look up and try to get the symptoms and that, but I think nowadays it's different, I think one ae the worst things you can do nowadays is look on the internet and*

try and self-diagnose because, I mean, you'll convince yersel you're dyin' like eh? You know I mean there's so much, information there eh?

It is worth noting that some of the more positive attitudes towards health information on the internet came from those who had gone online to look for information about a long term condition or illness after being given a diagnosis by a doctor. There is arguably a significant difference between looking up a particular diagnosis to get more information about it and just 'Googling' symptoms with the aim of self-diagnosis, which may account to some extent for the expressions of mistrust of the internet in this study which focussed on experiences of acute symptoms.

7.2.3 Limits to lay knowledge

The obvious limitation of experiential knowledge is that 'what is not experienced is not known' (Prior 2003: 48) and so, when a symptom is qualitatively different from anything previously experienced, as was the case with many of the symptoms which led interviewees in this study to call NHS 24, the limits of knowledge are quickly reached. While many interviewees of course drew on their own and others' knowledge in their decision-making, most were careful to construct themselves as mistrusting of lay knowledge, whether online information or the 'common sense' knowledge of other lay people. One reason offered by some people to account for this mistrust is that experiential knowledge quickly becomes outdated; as Gail explained when she said that she would never ask her mother for health advice.

Gail: *No, it's been donkey's years since she had us, so, and everything changes, I mean, even the changes between having Phoebe and having Craig, where to put them in the cot, you know what age they're allowed to eat solids and, it all changed, and there's only 3 years between them! You know so, nah, there's no point in speaking to my mum about it because, well, everything's changed, so.*

However, expert advice is not static either and the idea that people's own knowledge is informed by expert advice which is constantly changing was also mentioned by Andrea in relation to medicines advice for children and by Euan and Debbie in relation to basic first aid.

Andrea: *I'm... he's got the cold just now, but because of his age there's- there's nothing that you can give him now, ehm whereas before it was always*

kind of like Medised but now that's 6 and over, so, they basically say, well, just give him a wee drop of Calpol, or, let it run its course and-

Euan: *Cos when I went for mine and that was years ago it was 5 compressions, it was 5 and then blow, but now it's all changed eh?*

Debbie: *No, oors it was ehm, 30 when I done mine, but unless they're in water.*

Euan: *Aye*

Debbie: *Then it's 5 breaths in the mouth and then the compressions start for the water, so it all changes, it keeps on changin', it'd be better if they just kept it goin'.*

Many interviewees talked about how difficult it can be to assess the severity of symptoms and even for those who say they feel competent to self-care there are times when they just don't know the best course of action to take. As noted, this is often because they are faced with something they have no experience of, or because of a fear that relying on experiential knowledge may lead them to dismiss a serious symptom as trivial. As discussed in chapter 5, 'past frights' (Hopton et al. 1996) when people had misdiagnosed something with worrying results, could undermine confidence in self-diagnosis.

Doreen: *Sandra, the oldest one, had appendicitis, but the first few days she was saying, 'Oh, mum, I've got cramp in my stomach'. And I thought, periods? You know, she's 13. I says 'Och, take some para- paracetamol or something, you'll be alright'. And it just- for 2 or 3 days it's still there and then one day she come in fae school and she was yellow, you know, in her eyes, she just looked in real pain and I says 'Right'. So I phoned the doctor, he came straight out and he went 'Appendicitis', he says, 'I'll need to get her in right away'. And the ambulance came and took her in. But she was just saying, 'Ouch', it wasnae like screaming with pain.*

A number of people expressed particular concerns about not being able to assess the severity of symptoms in children, especially as small children are unable to communicate how they are feeling. This is compounded by a widespread understanding that children can change quickly and that symptoms which may not be worrying in an adult can be more serious in a child, as previously noted. This echoes the findings of Houston and Pickering (2000: 237) who noted that 'many parents expressed feelings of being ill equipped to manage the health-care problems of their

children' because they lacked confidence in their knowledge and abilities and feared doing something wrong.

Some of the interviewees used stories of times they *had* known how to deal with symptoms to illustrate that they had some level of knowledge about health and illness and to construct themselves as competent in self-care and caring for others.

However, some people wanted to emphasise that they did not consider themselves to have any medical knowledge at all.

Natalie: *But, I'm really aware that medicine is definitely a topic I know nothing about, and I- Now there's, there's general information, that everyone knows about, but when it comes to looking at things more in detail, then I don't think I would trust my own judgement to be able to tell what's right and what's wrong... Ehm... I would always be- even with science, I'd be like 'Is this pseudoscience? Is this accurate?' [laughs].*

It is important to highlight that the way people constructed themselves as both having knowledge and lacking knowledge was often complex and contradictory. This illustrates again the competing imperatives that people were negotiating in these accounts; constructing themselves at once as responsible in the sense of 'able to look after themselves and others' and responsible in the sense of 'seeking expert advice when necessary'. The following quote from Josie illustrates this, as she explains that she would not self-diagnose because she is not a professional, but then immediately moves into a story about a time when she knew better than a doctor.

Josie: *I'll look for advice and things like that, ehm, but I don't kinda like trawl through sayin' my symptoms are such and such, what could possibly be wrong wi me, cos it could be a multitude of stuff. You know, and then if I start diagnosin' meself- no I don't think so! I'm not an expert, I am not a professional.*

ED: *Yeah*

Josie: *You know they, they haven't trained for god knows how many years, eh, you know to have me sayin', ok there are- there's once or twice wi ehm, Max has got really severe psoriasis, ehm, and when he first started with it he were about 18 and I took him to t' doctors, and I said he's got psoriasis, 'Oh no, don't be silly that's not psoriasis' and it's, she came away with this other thing, and it was somethin' rosy and I said I thought rose were a bottle of wine! Eh, 'Oh no it will ehm, it will last for about 3 months, go away and*

he'll never have it again' and I says 'He's had it for a year now'. Eh, and it did turn out it was psoriasis...

These stories of 'knowing better' than clinicians were not very common in the accounts of participants and certainly the only person to openly challenge the recent advice they received from NHS 24 was Robert because it didn't fit with his understanding of his symptoms. However, some people did use stories in a similar way to Josie, to show that on other occasions they had been willing to challenge medical expertise in order to access treatment for themselves or their children. These stories showed that while usually privileging professional knowledge, people will not necessarily accept clinical advice if it is not in accordance with their instinctive knowledge of their own bodies or of their children, their experiential knowledge, or their common sense understandings of health and illness (Dew et al. 2014).

7.3 Lay consultation and referral

There were numerous examples of lay consultation in the accounts given by interviewees and many people had spoken to a friend or family member before their most recent call to NHS 24. Some interviewees had specifically asked someone else for advice but more usually they had just mentioned or discussed symptoms. Lay referral networks were much less extensive than those described by Freidson (1960), in line with other more recent work (Cornford and Cornford 1999). Lay consultation was often described as supplementary to or concurrent with professional consultation in interviewees' accounts. Gail had spoken to her sister, who is a nurse, before calling NHS 24, although she said that her sister hadn't advised her to seek further help and that she made the decision to call NHS 24 on her own. Heather had called her mother first, although she said that she had intended to call NHS 24 anyway. Debbie had tried to phone her mother before contacting NHS 24 as that's always the first thing she does if anyone in the family is unwell, but hadn't been able to reach her. Maggie had discussed her symptoms with colleagues at work and she also called her mother while waiting for a call-back from NHS 24. She said that her mother is usually the first person she phones if she's unwell.

There were many further examples of lay consultation in people's accounts of what they usually do if they are unwell. Andrea said that she usually talks to her husband as he stays calm and suggests things for her to try. Tracey said that she asks her mum for advice '*all the time*', as does Andy who also still lives at home. Claire said that she usually calls her mother, but that she would also talk to her 3 sisters who all have children. Katie, who said that she doesn't have much support as a new mother, nonetheless described turning to a number of people for advice and being able to use that advice rather than contacting formal health services.

Katie: *Yeah, I'd usually phone, eh, ma sister or I've got friends back home that've got babies, I'd phone them too, eh, yeah I'd usually do a general ring round first, eh, I think.*

ED: *Would you? Before you'd call NHS 24, or the doctor or something, would you do-?*

Katie: *Yeah, I'd phone a few people, like phone ma sister and ma dad and, ma friends and that [laughs]. I'm quite bad.*

ED: *And what do they say? Would they like, give you helpful advice?*

Katie: *Ehm, yeah sometimes, yeah, mmmhmm, ehm depending what it is, ehm, I freaked out about nappy rash, cos she had nappy rash [laughs] ehm, and I phoned my friend Andrea, and I was like [panicked voice] 'She's got nappy rash, and it's all red!' and she was like, 'Och, they just get that' and I was like 'Is it somethin I've done?' and she was like, eh, 'Nooo, it's just, it just happens, put cream on it' and I was like 'Alright' [laughs].*

Some of the mothers said they speak to other mothers about children's health but described it more in terms of sharing experiences or just noting that a bug is '*going about*' rather than asking for advice. It has been suggested that this is a way of learning without exposure to potential scrutiny or criticism (Neill et al. 2013).

Some of the accounts of lay consultation were quite contradictory. For example, Josie suggested that if her older children had been around when her symptoms became serious she would have been '*led by them*' in deciding what to do and she thinks they would have taken her to hospital. However, she later claimed that she is '*strong willed*' and that, although they discuss things as a family, she doesn't go to them for advice.

Josie: *You know, so ok we are quite a close-knit family unit, and we've got an extended family unit as well, but, we, we discuss things and that ehm, obviously because of Max, because of Scott, because of Joseph bein' blind, and that kinda thing, ehm, but he's also a diabetic you know so there's a lot to talk about. Ehm, and what's best for everybody else and what we can do to help each other out and that kind of thing, but, I don't know, no, when it comes to my health... I make the decisions.*

Josie also said that her children talk to her about health and ask her for advice, but she then corrected herself to say that they would go to the doctor and immediately followed with a story about a time that her youngest daughter had asked her for advice and she had told her to seek further help.

Josie: *Aye, you know aye, because I'm as old as I am, ehm... you know and kids will, you know and they'll say... well, in saying that no, they'll make an appointment, they'll go to t' doctor's, we'll talk about it but, I wouldn't say to them, obviously, 'Oh no you can't... don't go to the doctors' you know 'it's not worth it' that kind of thing. Eh, like me 2 year old granddaughter were found one mornin' biting, it were a, she'd pulled a soap powder thing out... and it were one of the liquid ones, and Kimberly said to me 'God mother this is in her mouth' so I said 'Right, get her to spit it, phone the national health', you know 'phone the doctors get their advice', she says 'It does tell you on the packet, you know that it could be caustic' I said 'Right well ask them and see what they say'. You know 'But clean her mouth first you know, get water and you know' cos she was like squooshin' water in her mouth and wipin' it out at the same time, and that's basically what they told her to do, you know but it's just confirmation of what I'm sayin' is, you know.*

This is quite typical of many of the interviewees' stories about lay consultation, in that Josie is keen to construct herself as knowledgeable and giving advice which is later confirmed to be 'right', while also showing that she and her family would seek expert advice rather than relying on lay consultation.

The likelihood that someone would consult a friend or family member about an illness often seemed to be related to the perceived seriousness of the symptoms. People said that they might consult a lay person about something that was just a bit worrying, or what Jodie referred to as 'a niggles'. Similarly, Paula thought that her own children would only ask her for advice if something wasn't serious.

Paula: *Ehm... I think that if it wasn't serious yeah, I don't think they would ask me if it was serious and they needed to just go, ehm I think that they're all*

pretty sure of themselves that they would just go, but yeah if it was something that they, if they were just a wee bit worried about then they would just pass it by me or whatever and say 'Do you think-?', and I would say 'Well, what's he doing or what's she doing and, how is she, is she hot, blahblahblahblah', and yeah, so yeah they would.

This was particularly emphasised with regards to illness in children and was important in the construction of responsible parenting, as discussed in chapter 6. Even Debbie and Euan, who trusted greatly in Debbie's mother's knowledge and would always call her in cases of illness, were careful to point this out.

Debbie: *Aye, phone mother. Mother knows best.*

ED: *For you and for the kids as well?*

Debbie: *Aye, for the bairns as well, aye. Mother's ayeways the first yin to phone and if she cannae answer it then we look for other options, but no mother's ayeways first choice. Aye [laughs]. And I'm a first-aider [laughs].*

Euan: *Unless it's serious wi the kids, like last time and that wi the, the temperature and that. But that's no muckin' about that's straight up to the sick kids and that.*

A very common response from interviewees when asked if they ever seek advice from friends and family about health and illness was to mention a family member with some form of clinical knowledge or expertise. This has previously been noted by Blaxter and Paterson (1982: 155), as the limited lay referral system used by the mothers in their study 'consisted largely of people thought to have special knowledge, rather than being an extensive network of consultation among neighbours and friends'. Peter and Claire both said that they would usually call their mothers for health advice as they are nurses. Angela is a health visitor herself, but she said that she would call her mother-in-law, also a nurse, for advice. Paula, Katie and Gail all have sisters who are nurses and would speak to them if they had questions about illness. Lauren has previously asked her step-mother, who is a doctor, for advice. Tomasz's wife Irena has doctors in her family in Poland and he thought she might discuss child health with them on Skype. The importance of reference to those with clinical knowledge will be discussed in section 7.4.

Lay referral to formal help

When people had discussed symptoms with someone else before their recent call to NHS 24, there were some examples of referral to the professional sector, such as Peter who decided to call on the advice of his brother in law; Alison who said that it was her daughter who told her to phone; and Tracey who had been advised to call by her mother. Jim had spoken to his wife and she had advised him to call NHS 24; he didn't think he would have called if she hadn't suggested it. There were also examples where interviewees discussed their symptoms with someone who then made the call to NHS 24, so Josie's daughter had phoned on her behalf, Tina's husband had phoned for her and Euan had phoned for Debbie.

Many interviewees suggested that if they were advising someone else who was unwell they would usually direct them to formal sources of care. Maggie explained that if someone was sick with something like a 'bug' she would try to help them herself first, but that 'if it sounded like it was anything remotely serious' she would advise them to phone NHS 24. Both Doreen and Paula were clear that they would advise their children to seek help for their grandchildren if they thought it was necessary.

Doreen: *Aye, I know. And I, I mean, you canna really, if I thought it was something serious, you know, I would say, phone the, the 24-hour service, you know. Which they do, they usually do, you know, if it is something serious. They would phone for the kids anyway. For themselves, I don't think they would bother as much. I don't think I would. I usually say, 'Och, I'll just go to my bed and lie down a wee while and see if it's alright', you know.*

Paula: *Yes, yes, well Rob'd ring up with the girls and Sally and Rebecca will just ring up and say you know 'What do you think?' or whatever. And, it's normally things like teething or you know something like that, ehm, but and they will say, like ehm, Rory actually has just been in hospital, he had an asthma attack ehm, so, yeah when he was like that I said to her 'If he can't breathe get him in to hospital' you know, ehm, so, yeah we do talk about it on the phone yeah.*

Doreen and Paula are displaying similar attitudes here to the majority of the grandmothers interviewed by Blaxter and Paterson (1982: 177) who said that 'they would not recommend their own remedies, and that their advice was usually confined

to encouraging their daughters to consult a doctor'. Again it is clear here that the extent to which people feel confident and competent to advise others is linked to the perceived severity of the symptoms and the extent to which the illness they are being asked about is something they are familiar with. This may be a result of risk-aversion and fear of being responsible for, or blamed for, an adverse outcome. It is also likely that interviewees wanted to emphasise their responsibility by demonstrating that they would always tell others to seek expert advice.

7.3.1 Reasons for not consulting others

A key reason given by those who said they do not consult friends or family about illness is that they don't know anybody with clinical expertise. In explaining this, Laura again highlights the difference between asking for advice and just sharing experiences or keeping others informed.

ED: *And what about ehm, friends or family and people like that, do you, are there people that you would call if you were worried about something or looking for advice on what to do?*

Laura: *Ehm... I don't think so, cos we don't have anyone in the family with a medical background. We have lots of, ehm, primary school teachers who have stories of all sorts of infections and ehm, but no, I wouldn't, I would perhaps phone them, you know for my peace of mind, but not for, not for...hmm, that wouldn't be who I would phone first, mmmhmm. For example when I used NHS 24, I phoned my mum afterwards, to tell her 'Oh my goodness the children have got chicken pox', but I wouldn't phone her first, no, no.*

Another reason that people gave for not consulting friends and family about illness was that their symptoms were part of an ongoing problem or something that they had experience of. If they knew what was wrong, there was seen to be no point in asking other lay people for advice. For example when James experienced back pain, because it was a recurring problem, he knew that he just wanted a prescription for strong painkillers so he called NHS 24 straight away to try to get an appointment.

Both Lauren and Tomasz specified that the reason they don't speak to anyone else about health problems is that they don't have any. This highlights an important aspect of exploring illness behaviour with people who consider themselves to be healthy and are keen to construct themselves as such. There was an impression from

both their accounts that illness is not something they give much consideration to and that it has little bearing on their day-to-day interactions. Lauren said that she has better things to talk to people about than her health and Tomasz said he doesn't feel the need to include family members in *'that kind of stuff'*. Similarly, Natalie explained that her wish to construct herself as healthy was one of the reasons that she wouldn't speak to other people about symptoms and this was an attitude that she felt was held by others in her family.

ED: *And are there other people that you would call, like other family members or friends or anyone that you would talk to about health issues or ask advice from?*

Natalie: *Ehm... not really. If I was ill I'd obviously mention it to my husband, but... I don't like, in my mind, I am a healthy person, and although I'm, you know, anaemic and tired sometimes, and I've had pneumonia and bronchitis and that all in the past, I still consider myself quite a healthy person. And so I don't really, and I like other people to have this impression of me as well. Ehm, so I don't necessarily like mentioning that I feel, like if I'm feeling ill. I think, I do get embarrassed about it. Ehm, but it's, it's the same, I mean, my mother is severely asthmatic, and she got ehm, pneumonia, 2 years ago, at Christmas. But she didn't tell anyone cos she didn't want to spoil anyone's Christmas, so she eh, just pretended that she was absolutely fine, and we didn't find it out until, you know, she was rushed to A&E.*

ED: *Right.*

Natalie: *So I think it's just, just kind of 'what we do' [laughs].*

ED: *So it's quite common in your family to not share that kind of thing? Ok.*

Natalie: *I mean we're quite a close family generally, ahm, we, we outn- like the girls outnumber the boys and we're- I'm one of 3 girls, my mother's one of 3 girls and 2 boys and, all the sort of- so we are quite a close family generally, but not over health concerns.*

Natalie also thought that her mother wouldn't have knowledge beyond what she herself could access, despite her mother's nursing background. She felt that her attitude to lay consultation would be quite typical of her peer group and was surprised that I asked her about discussing symptoms with her family at all.

Natalie: *I think... my friends, my acquaintances, and in fact even my family, would phone NHS 24, or go to the doctor's, or look on the internet, long before they'd ask their family [laughs]. Ehm, I think certainly I would feel, well if I don't know this information, my family won't know this information.*

So I either do the research myself or I phone somebody who I do know will have the information. Ehm, whereas if something is actually wrong with me then I feel there is nothing my family can do about it! [Laughs] And I should just go to the doctors...

While many of the interviewees in this study are undoubtedly engaged in lay consultations, the nature of these is ambiguous and the types of symptoms that people consider it appropriate to consult on are usually limited to those about which lay people might be expected to have knowledge. People often clarified that they would ask advice for very minor things but would seek professional help for anything that they considered to be serious. The exception to this is when people have a close friend or family member who is also a health professional, which blurs the boundaries of 'lay' consultation somewhat. People also emphasised referral to sources of professional advice in their accounts of their own lay consultations and in considering what they would do if others asked them for help. This privileging of professional expertise was a notable feature of many accounts.

7.4 The importance of professional knowledge

The importance of 'professional' knowledge was repeatedly highlighted throughout the interviews in the terminology that people used when talking about their reasons for calling NHS 24 although, as noted in chapter 4, not everybody was sure about the level of expertise of NHS 24 staff. For example, Peter said that he wanted to speak to somebody to get '*professional or semi-professional advice*', and Andy said that he called because he wanted to get '*some professional advice from a nurse or somebody from a medical background*'. Josie said that her daughter had phoned NHS 24 because she knew that Josie would only accept health advice from a professional:

Josie: *You know, and I think if you spoke to her and asked her why she phoned, that's what she'd tell you. You know, 'Me mam's more likely to listen to a doctor when it comes to medical things, or a nurse, than she is to me'.*

ED: *And is that true?*

Josie: *Yes. Because they're professional, she's not. You know.*

Maggie said that she called because she was looking for '*knowledgeable advice*', while Tina used the terms '*qualified*' and '*professional*' when explaining what she expected from NHS 24.

Tina: *Well I don't know what ma husband was expectin', I was just, thought maybe there'd be just a qualified adviser there, you know, that could say well, I'll get back to you in 5 minutes or, I'll have a, go and ask somebody, a professional, and get back and give you the advice. But I mean, I've never used it before so I didn't know.*

Paula referred to contacting '*a professional that actually knows what they're talking about*' and Steven said that he likes to speak to a person '*that knows what they're doing*'. For Euan and Tracey, the feeling that the person they had spoken to knew what they were talking about was important in terms of their satisfaction with the advice they had been given.

Euan: *The lassie was really nice, the guy was really nice, we didnae wait, I mean you're talkin' minutes before I got to speak to a staff nurse, and somebody who knew what she was talkin' about and that, eh and fae there on everything was fine.*

ED: *And how did you feel about that advice?*

Tracey: *Ehm, alright, I think it kinda makes you feel better to know that you've spoken to someone, do you know what I mean? Someone that you know that knows what they're talkin' about.*

Similarly Tomasz, when asked how he felt about his experience of using NHS 24, replied that he was confident that he '*was dealing with professionals*'.

What is also interesting here is the importance of speaking to a *person*, suggesting that it is not just the expert knowledge that is valued but the embodied expertise and the ability to access it from another human with whom interaction is possible, rather than from a virtual source.

Peter: *Yeah I'd certainly rather speak to somebody in person rather than, sort of, looking- I mean websites, you know websites are fine but when it's somethin, somethin like that I think I'd rather speak to somebody and get professional or semi-professional advice there and then, rather than trying to sort of diagnose somethin myself online. Ehm...*

Euan had not been aware of the NHS 24 website and had only looked online to find the number to call but he said that he would *‘rather speak to somebody than a computer’* even though he is comfortable with technology and uses a computer *‘all the time’* because, he says, *‘you get a better diagnosis’*. The importance of speaking to a human has also been noted by Rubin et al. (2010) in relation to NHS Direct and Firth et al. (2005: 13) suggest that the desire to engage with someone may be a result of, rather than in spite of, the widespread availability of text-based information. Kivits (2006: 276) has further suggested that *‘it is the threat of misinformation that information seekers face on the Internet that leads interviewees to emphasize the essential role of doctors as their primary health information source’*. This was echoed here as use of the internet was sometimes considered to be dangerous and the fact that someone on the phone can ask *‘specific questions’* and give personalised advice is seen as less risky.

ED: *And do you use anything like, do you use the internet, to kind of look up health advice?*

Julie: *Sometimes we do that daen’t we?*

Steven: *Sometimes but very w- I’m very wary of it. Because you can-*

ED: *How come?*

Steven: *Cos you can type in what you think, and it can come up with loads of different answers... I mean you can type in a cough and it can come up with everything from bronchitis to a cold! [laughs] So.*

ED: *Yeah. So you wouldn’t feel confident kind of using it?*

Steven: *I would rather speak to someone on the phone. Cos they can ask you the specific questions.*

ED: *Yeah. And is it the same with books and leaflets and things like that?*

Steven: *I wouldn’t really... Nah, I like to speak to the person, that knows what they’re doing rather than try and self... self-diagnose. Can be dangerous I think. [laughs]*

While the accounts presented so far in this chapter demonstrate the diversity of sources of knowledge that people draw on when making decisions about symptoms, the prevalence of references to professional knowledge suggests that for most interviewees it is considered to be more legitimate than their own knowledge and that of other lay people, as illustrated by a comment from Gail.

Gail: *They just had to confirm what I already suspected, you know, and because, because it was somebody who knew what they were talkin' about then you take, you take it as gospel. You know. But had that been any Tom, Dick and Harry then I probably wouldn't have believed them. [Laughs] ... I always look up to nurses because I think that they know what they- they're on the front line, you know...*

The idea that professional expertise is more legitimate than popular or lay expertise has been suggested elsewhere (Stevenson et al. 2003) but it contrasts with the findings of Dew et al. (2014) who suggest that medical professionals are not always seen as the most trustworthy source of advice and that people construct different hierarchies of knowledge depending on the type of 'wellness practices' they are engaging in. However, the difference may be accounted for in that the present study was focussed on specific instances of acute illness, which 'is likely to shift the focus of trust onto a narrower range of influences' (Dew et al. 2014: 40).

7.4.1 NHS 24 and the accessibility of professional knowledge

It is difficult to establish the extent to which people might be turning to NHS 24 for advice rather than to alternative sources. However, I did ask interviewees a hypothetical question about what they thought they might have done if NHS 24 had not been available on the occasion they called. Their responses were diverse, but the majority said that they would have tried to access professional advice in another way. Alison, Lauren, Andrea and Grant all said that they would have gone straight to A&E if they had not been able to obtain advice from NHS 24. Euan said that he would have taken Debbie to the hospital and Irene said that she would have gone to the hospital if her symptoms had gotten worse. Josie doesn't know what she would have done but thinks that she probably would have gone to the hospital and Angela would have gone to the hospital as she knows that there is an out-of-hours GP service based there. Robert would have gone to the hospital and that is what he did anyway when he didn't get a referral from NHS 24. Andy and Paula both said that they might have waited until the doctor's surgery opened, or they might have gone to hospital, depending on how bad their symptoms were. Tracey and Jim said that they would have waited until the doctor's surgery opened the next morning. Tina said that she would have panicked and she would have tried to contact a pharmacist for advice or

tried to work out the best course of action by herself. John said that he would have panicked and phoned his nearest A&E department to speak to a staff nurse, which is what he does anyway if NHS 24 is busy. Tomasz also thinks he would have called the hospital and asked to speak to a nurse and only if that approach didn't work would he have tried to contact one of the doctors in Irena's family for advice.

Very few people said that they would have turned to family for help. Maggie thinks she would have panicked and phoned her mother but that if her symptoms had then worsened she would have gone to A&E. Peter thinks he might have phoned his mother but he also might have phoned the doctor to get an appointment. Laura thinks she might have turned to family but that she would have expected them to then advise her to go to a hospital anyway as her baby was only a week old.

ED: *So what do you think you would have done then, if NHS 24 wasn't available to you?*

Laura: *Ehm... I've never thought about that before. Ehm... what would I have done? ... [To baby] What would we have done Jane? Ehm... Gosh that's a very good question... I probably then would have phoned family, more, you know I would have phoned my mum, I would have phoned [husband]'s mum. Yeah. Uhuh.*

ED: *Is it the sort of thing you would have taken her to hospital for?*

Laura: *Yeah. I think I would have phoned my fam- you know, my mum and then [husband]'s mum, and then had, they would've probably said take her to hospital. You know. Ehm because she's so small. So that probably, I probably would have taken her to [children's hospital], I think, uhuh, uhuh.*

Although Natalie emphasised that she would not ask her family for advice, as noted above, she thought that she might have phoned her mother had she been unable to access NHS 24 but added that this would have made her uncomfortable.

ED: *Ehm, what do you think you would have done in that situation if NHS 24 wasn't available?*

Natalie: *[long pause] Ok, this is going to sound awful, since maybe in retrospect I should have done it in the first place, but I think I possibly would have phoned my mother. [Laughter] Yeah. I don't like admitting to health problems to my mother though.*

Claire would have brought her child straight to A&E in this instance, because of her worrying symptoms. However, Claire is from Ireland, where there is a cost for GP

appointments and A&E attendances and she also reflected that if she had to pay for everything she might rely on family and friends much more in less serious circumstances, suggesting that barriers to access (in this case financial) may in other circumstances make people less likely to seek formal help.

Claire: *I think... I think if you were paying for everything you would definitely use family and friends an awful lot more. Cos chances are they've been through the same kind of situation... I think so. Yeah.*

ED: *It's interesting that you have that contrast as well, that you can sort of-*

Claire: *Yeah. The fact there's a free service over here is fantastic, and I think people do make more use of it for that reason.*

Very few others mentioned the idea of cost in relation to health service use, perhaps unsurprisingly as it is not something that those who are used to the NHS need to consider, but some did talk about accessibility; for example Tomasz suggested that the easy accessibility of professional advice makes people more likely to use it.

Tomasz: *Yeah people overreact, quite often. Eh, every silly thing and, like high temperature [laughs]. And they call, they bother- nah it's... Yeah I think that people tend to consult professionals more than, than they used to in the past. Maybe they were not as accessible, in the past.*

ED: *Do you think that might be the reason? That it's easier now?*

Tomasz: *It's much easier, yeah, you just pick up the phone or just turn on the computer and you can access quite a lot, information and well that makes you hypochondric [sic], to some extent.*

Laura returned to the idea that lay support would have been more accessible in the past than it is now. However, when she thought about it further, she added that there would also have been an element of necessity to using lay advice when expert information was less accessible.

Laura: *'Oh my goodness! Oh my goodness, he's got spots, oh! Oh, I need to phone NHS 24!' Whereas, in my, my parents' generation as parents, you know grannies were around the corner and your neighbour said 'Oh it's just chicken pox, my little boy had it last week, just get on with it'. So, yeah I think there woulda been a m- a be-, not better, ehm, more accessible system of support in place 30 years ago.*

ED: *And do you think it was just closeness of, sort of geographical closeness or-?*

Laura: *Ehm... I think, no, I think it's a lot of things, I think it was closeness, I think it was, ehm, lack of technology meant you needed to ask people advice, ehm, eh, you know people didn't have iPhones and laptops and iPads and, so you had to speak to, to other parents and, ehm, at playgroups and nurseries and, you know at the school gates and, I don't just think it was geographical, no, no.*

Similarly, Natalie suggested that the accessibility of information via technology removes any need to ask friends and family for advice about symptoms.

Natalie: *I suppose people must have asked their families, before the internet, back in the dark ages. I mean where else would you get information from? Mmm. [Laughs]*

Both Natalie and Laura said that they would look online as a first port of call if they wanted advice rather than asking family; however, it is not clear from these comments if they are equating the information available online to lay knowledge or to expert knowledge.

The accounts presented here raise an interesting counterpoint to the idea that people have come to depend on health services due to an absence of lay support. Rather, they suggest that people would only rely on lay knowledge if professional advice was inaccessible, perhaps for reasons of cost or inconvenience. Certainly some interviewees mentioned that the accessibility of NHS 24 was part of the reason they chose to use it rather than seeking help from other sources. Calling NHS 24 was seen as easy and convenient compared to what was described as the difficulty and hassle of accessing GP appointments or travelling to a hospital. Therefore, while some people may access NHS 24 due to a lack of available support in the popular sector, it seems likely from these accounts that for many more it merely represents easier access to the professional sector. Given that lay knowledge is often seen as inadequate when dealing with serious or unfamiliar symptoms, and that professional knowledge is so highly valued, it is not surprising that many people would choose to speak to a professional if both sources of advice were equally accessible.

7.5 Summary

While the 'geographical discourse about the morality of kinship' (Mason 1999: 156) seems to have become a dominant framing of accounts of other people's over-use of

or over-reliance on health services, it has been described as ‘at best contentious’ (Hanlon et al. 2003: 8) and is inadequate to explain why interviewees in this study contacted NHS 24 about the symptoms they were experiencing. In spite of the changing shape of families and care, most people in this sample do have access to the support of family and friends. Interviewees talk about sharing experiences of health and illness, discussing symptoms with others, and sometimes asking other people for advice. However, when a symptom is particularly severe or unfamiliar, most people report that they would seek professional help.

Illich (1976) describes what he calls the ‘expropriation of health’, whereby lay people have lost confidence in their ability to care for themselves and others in a family or community setting. With the expansion of the power and authority of the medical profession, Illich argues, lay knowledge has come to be regarded as inferior to that of professionals. Such theories of medicalisation, which allow little room for the individual agency of lay people, have legitimately been challenged as overly-simplistic (Williams and Calnan 1996a). However, while the reality of health care use is complex, people do seem to have, at least to some extent, accepted the idea that medical knowledge is so specialised that attempts by a lay person to attain or apply it can be ‘dangerous’. There is also a sense, as discussed in the previous chapter, that being a responsible patient or parent entails seeking professional advice about symptoms.

It is interesting to note that while people often mentioned wanting to speak to a ‘professional’; the nature of the profession in question was not specified. This suggests that the ‘professional’, rather than necessarily being someone with a particular qualification, is instead a symbolic category (Becker 1962) in which people feel they can trust (Giddens 1991; Daniel 1998). At the same time, it was important for many people to speak to a *person* suggesting that the embodied nature of the expertise is significant and that being able to engage with someone at a time of anxiety matters to those making decisions about symptoms.

While clearly privileging professional knowledge, this data shows that lay people do incorporate knowledge from a range of sources into their decision-making, and are

by no means passively compliant with professional advice. However, the idea that access to information via the media and the internet is significantly enhancing people's ability to self-care is not supported by these accounts, or by the fact that calls to NHS 24 continue to rise even as more and more information is provided on its websites. When it comes to assessing minor symptoms, the internet is seen as having limited utility and even those who do use it treat the information available with considerable scepticism. Many people do not want or feel the need to search for information and are happy to rely on the opinion of a health professional; this is clear from the accounts of participants in this sample, and similar results have been found elsewhere (Henwood et al. 2003). Even in studies conducted with people who do regularly use the internet to search for health information, respondents readily acknowledge their own lack of expertise and ultimately say that doctors are their main source of information (Kivits 2006).

I suggest that while social and demographic change may well contribute to changes in illness behaviour and help-seeking, the evidence from this study suggests that such an explanation is inadequate. Easy access to valued professional advice is more likely to account for why people call NHS 24 when interpreting and dealing with symptoms, rather than relying solely on lay knowledge.

8. Discussion and conclusions

The provision of out-of-hours health care in Scotland has changed significantly since the introduction of NHS 24 and the role of the organisation has changed accordingly. NHS 24 was introduced as a 'gateway' to the NHS, to help people to negotiate a complex health care system and to determine the best course of action when faced with illness. However, rising demand for the service following the introduction of the new GP contract in 2004 led to attempts to limit use of NHS 24, in the out-of-hours period, to situations which are considered to be 'urgent'. In this thesis I have engaged with the complex and ambiguous construction of 'urgency' and suggested that terms such as 'minor', 'urgent' and 'emergency' are both subjective and contingent.

While discourses about the 'inappropriate' use of services and campaigns such as 'Know Who To Turn To' suggest that there is a 'right' course of action when deciding what to do about symptoms, this requires individuals to be able to interpret, assess and categorise their symptoms in a formally 'rational' manner in order to determine the right thing to do in any given situation. Although, for some people, calling NHS 24 may be part of the process of symptom interpretation and decision-making, it can also be understood as one of a number of different points of access that people must choose between and use 'appropriately'. The messages that NHS 24 provides about its purpose, suggesting that it is an 'urgent care' service which also offers information, advice and reassurance to promote self-care, arguably create ambiguities which must be negotiated by callers in determining how, when and for what purpose they should use the service.

In this research, I aimed to explore the factors which led people to decide to call NHS 24 in the out-of-hours period about symptoms which, on assessment, were found to be suitable for self-care. I sought to understand their decision in the context of their illness behaviour and attitudes to service use more generally. I was particularly interested in how people interpret symptoms as needing or not needing attention, how they determine the most 'appropriate' course of action and what is understood by appropriate help-seeking in the context of calling NHS 24. I aimed to engage critically with constructions of urgency in order to understand how people

select routes to care. While the focus of the thesis has been on individual accounts of help-seeking, my approach was influenced by the ideas of Giddens (1984), in that I have considered the micro-sociological processes of individual decision-making to be inextricable from the social structures and values in which these decisions are made. Equally, individual actions are shaped by and in turn shape and (re)produce social institutions, including health services.

In this concluding chapter, after highlighting the strengths and limitations of the study, I discuss the findings of my research and return to the questions I have posed about why people call NHS 24 and how the service can be understood in the context of the wider health care system. For clarity, I have structured these findings in terms of ‘understanding NHS 24’ and ‘calling NHS 24’. However, I argue that they cannot be easily separated, as understandings of NHS 24 shape how people use it and experiences of use in turn shape how people understand the service. I then set out the implications of these findings for policy and for NHS 24 practice and suggest areas for further research and theoretical development.

8.1 Strengths and limitations of the study

Some of the methodological limitations of this study have been discussed in chapter 3. In this section I will further reflect on these challenges, as well as others related to the analysis and theoretical development. Completing this research project has been a significant learning curve; for example, had I understood the challenge of recruiting via gatekeepers early on, I may have spent more time than I did explaining my research to the staff in NHS 24 and supporting them to identify the types of callers I wanted to speak to. I would also have asked them to record the number of people they asked to take part who declined and any reasons given, in order to allow me to develop a clearer picture of why people may not have wanted to participate. I noticed that there were a few key staff who recruited well into the study; perhaps these staff could have been ‘research champions’ of some sort and supported others with recruitment. However, I was always aware of the additional burden I was placing on staff and was reluctant to impose further either by being present or demanding additional information. There is, of course, likely to have been some selection bias in

the sample of interviewees in this research as a result of the use of gatekeepers, as some staff admitted to only asking people who they felt were satisfied with their calls and those who agreed to interviews were also likely to have been positively disposed towards the NHS. Nonetheless, the sample was diverse and the data did contain criticisms of the NHS in general and NHS 24 in particular. Moreover, there were many advantages to this method of recruitment, particularly in the access it afforded to callers soon after their call and the ability to recruit those with a self-care disposal - a group that would have been otherwise difficult to access.

I also highlighted in chapter 3 the methodological challenges of researching everyday illnesses that may not be considered significant, in retrospect, by those who experience them. Focusing the research on the experiences of a diverse sample of people who were given a disposition of self-care advice was both a strength and a limitation. It was a strength in that the identification of the best course of action for ambiguous symptoms is problematic for callers, while the use of NHS 24 for what might be considered to be minor illness is problematic for the service; therefore it is an area of significant interest and importance. The limitation is that this is only one type of call received by NHS 24 and the outcome of 'self-care' is only one way of identifying calls about 'minor' illness. It is of course possible that many symptoms that might be defined as minor are in fact referred onwards, and this study did not explore that process. However, the data were sufficient to examine the complexity of factors that lead people to call NHS 24 about symptoms that are suitable for self-care and it was this process that was my analytical focus.

Had I known when starting out on this research how useful and important the observational fieldwork and the perspectives of NHS 24 staff would turn out to be, I would have sought ethical consent to record my observations more formally and to use them as data, although this would have had an influence on the relationships I was building with NHS 24 and may have limited how openly people were willing to speak to me. I would also perhaps have carried out more focus groups or interviews with staff, adding an additional dimension to the study, although time and resources may have prevented this. Furthermore, if the ethical and resource challenges could be overcome, it may have been valuable to have looked at call records or to have

listened to the calls made by participants, either before or after interviewing them. Although I was interested in the interviewees' accounts, rather than the 'truth' of what happened when they called NHS 24, it would have been interesting to explore the ways in which they and the advisers they spoke to constructed their symptoms and arrived at the call outcome. This would have added an additional layer of data to the study and may be something that would be of value in future work.

There was a conceptual challenge in iterating between some of the theories used in this thesis and the data I was drawing on. For example, while I found the concept of the 'risk society' very useful, because risk theory has rarely been applied in the way in which I have used it, I found it difficult to link it directly to the data and instead had to develop new ways of talking about risk that are informed by existing theory but fit with the accounts of my participants. Although challenging, using concepts developed in social theory, such as risk and responsibility, enabled me to make sense of interviewees' accounts in novel ways and extended the contribution of the research beyond the small sample on which it was based. Similarly, while I found Kleinman's model to be an extremely helpful heuristic device to allow me to conceptualise the health care system early on, and while it allowed me to raise interesting questions about how to understand NHS 24, the ambiguity and broad range of understandings apparent in the data made it very challenging to easily situate NHS 24 in the model. However, the concept of the boundaries between the sectors was analytically useful and in section 8.2.2 I discuss further how I have come to understand NHS 24 as operating at the intersection of and boundaries between the popular and professional sectors, a key analytical focus of the thesis.

In spite of the limitations noted here, I have been able to gather deep and rich data about people's understandings and experiences of calling NHS 24. While the accounts presented in this thesis cannot be claimed to be empirically generalisable, they have allowed me to raise and explore areas of important theoretical interest as well as policy and practice relevance. In particular, the findings presented in chapter 4 in relation to how staff and callers understand NHS 24 are a unique and novel contribution to our knowledge of health service use in Scotland. The insight this thesis affords into how reassurance is provided to callers not only through

interpersonal interactions but also through some of NHS 24's processes will be useful for the organisation to reflect on further, as will the increased understanding of caller expectations and experiences. The remainder of this chapter discusses some of the most significant findings and their implications in greater detail.

8.2 Understanding NHS 24

Help-seeking decisions are complex and influenced by a broad array of factors. Previous research has highlighted how the organisation of the health care system is one determinant of help-seeking as people make decisions in light of the choices available to them and the accessibility of services (Blaxter and Paterson 1982; Campbell and Roland 1996; Dixon-Woods et al. 2005). In chapter 2, I outlined the case for an orientation toward organisations in medical sociology and in particular for an understanding of the clinical encounter as not just an interpersonal interaction but as situated within a complex interplay of organisational, social and individual practices (May 2007). In order to provide this social and organisational context for my analysis of individuals' use of NHS 24, chapter 2 included an extensive description of the social and political environment in which the organisation was established as well as the ways it has been represented to the public. I suggested that the establishment of NHS 24 was a response to the policy aims of increasing individual responsibility for health and managing demand for care. However, I also suggested that a further aim of NHS 24, which is to improve access to other health services, is perhaps inconsistent with these policy drivers.

Research engaging with NHS 24 is extremely limited. Almost all of the existing literature arose from the evaluation of its implementation and deals with early successes and challenges in terms of establishing and integrating a new health service (Heaney et al. 2005; Haddow et al. 2007; Roberts et al. 2009). A lot has changed in NHS 24 since its implementation as it has reacted and responded to changing demands from government, from other health boards and from patients. A lack of research into staff and caller perspectives means that little is known about how it is currently understood by those who provide and use the service. I suggest that NHS 24 has conveyed, and continues to convey, conflicting messages about its

aims and purpose and that in attempting to both improve access to health care while also managing demand, it is attempting to fulfil two seemingly incompatible roles. As well as a gap in our knowledge of callers' understandings of NHS 24, there is a theoretical gap in terms of how to understand this organisation sociologically. This section therefore discusses my empirical findings related to how people understand NHS 24 and the theoretical implications for how we might conceptualise NHS 24, in the context of the health care system, as an organisation at the boundary of the popular and professional sectors.

8.2.1 How staff and callers understand NHS 24

In the absence of existing qualitative work with NHS 24 staff and callers, this research must be situated in relation to what is known about understandings of similar services in England and Wales, with the acknowledgement that out-of-hours services may be provided differently in other parts of the UK where NHS Direct was not established as a national service. A Welsh study (Egbunike et al. 2010) has shown the ambiguity in people's understandings of the role and purpose of out-of-hours primary care and, in particular, the mismatch between staff and patient understandings and organisational objectives. In that research, staff providing the out-of-hours service saw it as an emergency resource while patients understood it as an extension of usual primary care provision. My findings are similar to those of Egbunike et al. (2010) in that they highlight ambiguity about the role of NHS 24. It became clear in my analysis that there is a range of understandings of the service which diverge on views about whether it is for emergencies, urgent care, minor symptoms or general advice and support. The staff I spoke to during observation and the participants in the staff focus groups generally stated that they see NHS 24 as an emergency service, while callers had a broader range of views and expressed much less certainty.

Interviewees, and lay participants in the focus groups, often had limited awareness of how NHS 24 is structured and staffed, of how it fits into the overall health system in Scotland and of whether it is a 24-hour or out-of-hours service. The callers I interviewed variously understood NHS 24 as an emergency service, as an alternative

to or replacement for primary care or, as Maggie described it, *'like phonin' your mum, [...]except she's got a medical dictionary beside her'*. This diversity of understandings has implications for how people construct 'appropriateness' in relation to calling NHS 24. Some people draw on discourses of resource use in which NHS 24 is seen as less resource intensive than other health services. However, others worry about their use of the service because of their awareness of messages about a health care system in 'crisis' and, particularly, as a result of the recorded message they hear when they call NHS 24 stating that it is for patients who require urgent medical attention that cannot wait. In research on NHS Direct, Goode et al. (2004a) found that callers were less concerned about appropriateness when accessing that service than when accessing other health services; however, they cautioned that increasing demand could change this as people became more aware of pressures and the service became less able to respond flexibly to their needs. In the case of NHS 24, it may be considered that this prediction is supported as it is the restriction to urgent care, introduced as a response to rising demand, which instils anxieties for both staff and callers about whether or not use is appropriate.

Although the staff I spoke to see NHS 24 as an emergency service, they also see themselves as providing a valuable service for people needing advice or reassurance. They are willing to construct use of the service for minor symptoms as legitimate in cases where they perceive the need for advice to be 'genuine' (Smith et al. 2001). While they have strong views on what constitutes inappropriate use of NHS 24, they are willing to act as advocates for patients who use the service to access primary care, as long as those patients are able to present their claims to care as legitimate. This echoes the findings of Hillman (2014) who explored the ways that staff and patients negotiate legitimacy in an emergency department and how this can shape people's access to resources. It was clear from the accounts of NHS 24 staff that calls which are deemed to be inappropriate can be reconstructed as appropriate when the motivations of callers and barriers to health service access via other routes are taken into account. This may lead advisers to enable people who are considered deserving to get seen more quickly face-to-face or, conversely, to deny people access if they are considered to be attempting to 'work the system'.

The suggestion from some staff that NHS 24 is for *both* emergencies and general advice, and that in some cases it is a legitimate route to routine primary care, demonstrates the flexibility of interpretations of the role and aims of the service from within the organisation. This flexibility is also visible in callers' accounts when they suggest that the service is for emergencies while at the same time acknowledging that their calls might not have been considered to be emergencies. Work on NHS Direct has previously emphasised the ways in which the service and its meaning are jointly produced and shaped by staff and callers in their interactions (Goode and Greatbatch 2005) in a way that centralises flexibility (Hanlon et al. 2003: 5) and those findings seem to be echoed in the context of NHS 24.

I suggested in chapter 4 that ambiguity around the role and purpose of the organisation may not really matter as long as people get safe and satisfactory care. However, the lack of clarity about what is meant by appropriate use of NHS 24 could lead to anxieties around calling, particularly in situations where the urgency of symptoms is unclear. There may also be reputational risks for the organisation if people don't know what its role is and how it is staffed, either as a result of unrealistic expectations going unmet or as a result of the shortcomings of other parts of the health care system being attributed to NHS 24. The ambiguous identity of the service may cause some tensions for staff in that there is a lack of clarity to their roles and blurred boundaries around their realm of responsibility. The accounts of staff suggest that they are also aware that the way the service operates, for example with different provision in-hours and out-of-hours, may sometimes cause confusion and frustration for callers. I have drawn on these ideas of flexibility in conceptualising NHS 24 as an organisation operating at the boundary of the popular and professional sectors.

8.2.2 An organisation at the boundaries

Research on NHS Direct has explored how nurse-led helplines operate at the boundary between health care and the commercial world of the call centre (Goode and Greatbatch 2005; Mueller et al. 2008; Snelgrove 2009), leading nurses to emphasise their professionalism in the face of organisational change and uncertainty

about new roles. Early work on NHS 24 also explored issues of professional and organisational boundaries as the service integrated into the health care system at both local and national level (Haddow et al. 2007). My research suggests that we might additionally consider the service as spanning a boundary between the popular and professional sectors of health care. Although Kleinman's (1980) model of the health care system has been critiqued as overly simplistic (Stevenson et al. 2003), I have suggested that it remains a useful heuristic device with which to understand not only the different sectors of health care but also the boundaries between them and the spaces where they intersect and interact.

NHS 24 can be understood as situated in the professional sector. It is a service staffed by people who operate within a biomedical model of illness and professionalised structures. However, given that NHS 24 is intended to enhance people's ability to care for themselves in the popular sector, it can also be understood as operating within that sector. I suggest that it can best be conceptualised as located within the space where the popular and professional sectors intersect and overlap, as shown in image 4, and as operating flexibly at the boundaries between these two sectors. It acts as a gateway to the professional sector for those who see it as an emergency or urgent care service, but also as a gatekeeper, deflecting approaches to the professional sector back into the popular sector. At the same time, it can be seen as supporting self-care in the popular sector for those who understand its role to be the provision of advice and reassurance.

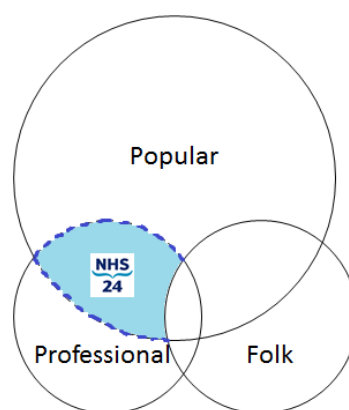


Image 4: Kleinman's model adapted to show the location of NHS 24 and the permeable boundaries between the popular and professional sectors

In chapter 2, I suggested that each sector is associated with a body of knowledge and I drew on the concepts of medicalisation and lay re-skilling to demonstrate how the boundary between the sectors is both permeable and shifting. Medicalisation is ‘more complicated than simply the annexation of new problems by doctors and the medical profession’ (Conrad 2007: 6); it can also be a useful concept in exploring the broader influences of the professional sector on practices of lay care. If NHS 24 has a role in supporting or enhancing the popular sector, then it is interesting to consider how it might be fulfilling this role and the impact this is likely to have. The findings of this study do not provide a straightforward answer and there are likely to be at least 3 different processes taking place.

Firstly, some of the participants in this study described turning to NHS 24 before seeking help from any other source, including friends and family. In calling the service, they were seeking advice, reassurance and, in some cases, referral to other sources of help. This type of first-line consultation and sanctioning of further help-seeking is associated with lay consultation (Freidson 1960; McKinlay 1973) and this suggests that, for some people, NHS 24 has come to fulfil a role that would otherwise be performed within the popular sector (Nettleton and Hanlon 2006). In relation to NHS Direct, O’Cathain et al. (2005) have suggested that this occurs ‘in a context of the delegitimation of the lay person’s ability to make judgements about their own health and illness, and their use of health services’ so that ‘people have come to need recourse to one health professional to determine whether they need to see another health professional’ (2005: 1769). In this sense, NHS 24 can be understood as encroaching on, or in Stevenson et al.’s (2003) terms ‘colonising’ the popular sector. Further weight is given to this idea when we consider that some interviewees suggested that they would have been more likely to turn to friends and family for advice had NHS 24 not been available.

Secondly, some participants reported that they do use lay referral networks; however, they expect to be told to seek professional help and that is the advice they would also give to others who were unwell. Some people sought lay advice after calling NHS 24, for example while waiting for a call-back. In this sense, lay consultation is being used both to sanction help-seeking (Zola 1973) and as a supplement to seeking

professional help. Alternatively, it might be interpreted that NHS 24 is being used as a supplement to self-care. This latter interpretation is supported in cases where people say that they would call NHS 24 if they experienced similar symptoms in future as they felt that it had been the ‘right thing to do’. In such cases, although NHS 24 is suggesting and sanctioning practices of self-care, it is not enhancing people’s ability to care for themselves in the popular sector without recourse to professional advice.

Thirdly, once advice is sought and reassurance is gained, some people describe themselves as confident to continue to care for themselves or others without further professional input; they may also feel that they would know what to do in a similar situation in the future and wouldn’t call NHS 24 again unless something was different. This suggests that in some cases NHS 24 is supporting, or ‘legitimizing’ practices of lay care in the popular sector. However, even when NHS 24 supports the popular sector, it is likely to endorse only those practices of lay care that fit within a biomedical understanding of health and illness. This could be seen as a form of ‘demedicalisation’, in that it is deflecting people from other professional services and encouraging lay re-skilling by giving people the confidence and capability to care for themselves or others at home. However, it is likely to be ‘a peculiarly medicalised form of demedicalisation’ (Williams 2001: 146) as it is lay care legitimated or sanctioned by the professional sector.

How we understand these processes is to some extent dependent on what we mean by the terms ‘self-care’ and ‘help-seeking’. In chapter 2, I noted the lack of consensus in the literature about whether or not self-care can include seeking professional help and suggested that seeking advice about self-care from sources in the professional sector, such as NHS 24, pharmacies or official NHS websites, occurs at the boundary between the popular and professional sectors. If self-care is understood as the actions taken by lay individuals *on their own* ‘to promote health, to prevent illness, and to detect and treat disease when it occurs’ (Segall and Goldstein 1989 153-154) then by definition, seeking help from NHS 24 cannot be considered to be self-care. If self-care can include interactions with the professional sector (Dean 1986; Pols 2012) then calling NHS 24 can be understood as part of self-care.

Questions about the meaning of self-care are therefore complex and, furthermore, what is meant by self-care and help-seeking in the context of calling NHS 24 is contingent on the various ways in which people understand and use the service. For those who see it as being an emergency service or ‘like a doctor’, calling NHS 24 can be understood as seeking medical attention. However, for those who see it as a service providing advice about the ‘right thing to do’ or reassurance that the self-care measures they are taking are adequate, it can be understood as supporting and enhancing practices of self-care. The conceptualisation of NHS 24 as operating flexibly at the boundary between the popular and professional sectors may offer a way to reconcile these different perspectives.

8.3 Calling NHS 24

This research builds on an extensive body of literature about illness behaviour and help-seeking. Research on why people consult about minor ailments (Cantrill et al. 2006; Leydon et al. 2009) has emphasised knowledge or lack of knowledge about symptoms and treatment, lack of confidence in self-diagnosis and worries that symptoms may be more serious than they seem. Research on help-seeking out-of-hours (Hopton et al. 1996; Drummond et al. 2000; Houston and Pickering 2000) has highlighted symptoms as the most important driver but has also found that worries about specific illnesses, the failure of self-care, lack of access or perceived lack of access to other sources of help and responsibility towards others feature in accounts. Previous experiences of illness and of health service use, particularly ‘past frights’, can prompt help-seeking (Hopton et al. 1996), although experience is also key to classifying symptoms as minor and avoiding help-seeking (Cantrill et al. 2006).

Qualitative research with callers to NHS Direct forms the basis of what is already known about help-seeking in the context of telephone triage helplines in the UK (Goode et al. 2004a; Goode et al. 2004b; O’Cathain et al. 2005; Rubin et al. 2010). This body of research describes how callers use that service in a variety of different ways to fulfil a range of different needs, such as to gain information about health, illness and health services, to question or confirm what has been said to them by other professionals, to seek reassurance and to challenge outcomes they are

dissatisfied with. There has been no research on help-seeking out-of-hours in Scotland since the introduction of changes to the way out-of-hours care is provided and no research published to date explores the views of callers to NHS 24. This thesis aimed to fill this gap in the literature by exploring the views of callers and their reasons for contacting NHS 24. The key findings here relate to risk and reassurance, responsibility and knowledge.

8.3.1 Risk and reassurance

The worry that symptoms might be or become serious has been identified as a trigger to consultation in previous studies of illness behaviour (Hopton et al. 1996; Kai 1996; Neill 2000; Hugenholtz et al. 2009; Leydon et al. 2009) and in this thesis I have used the concept of ‘risk’ to explore why people worry about symptoms which are not obviously serious or urgent from a clinical perspective. Whilst acknowledging that risk is a difficult concept to use because of its dominance in sociological theory and the very specific meanings which have become attached to it, I suggest that it is nonetheless useful for understanding the sense of vulnerability people feel when experiencing unfamiliar or potentially dangerous symptoms. While literature on risk generally speaks to global uncertainties, the concept of the ‘risk society’ (Beck 1992) is useful in understanding the social and cultural context in which people make decisions about dealing with symptoms.

Although the importance of understanding new forms of service provision in the context of the risk society was highlighted by the ‘NHS Direct: Patient Empowerment or Dependency’ project (Hanlon et al. 2003) and is discussed in a number of the outputs of that project (Goode et al. 2004a; Hanlon et al. 2005), that research focussed on ideas of reflexivity, citizenship and empowerment and did not directly apply the concept of risk to individuals’ decisions about acute symptoms. In fact, an understanding of concerns about acute illness has only been developed in the context of the risk society in one study that I am aware of (Hugenholtz et al. 2009), which focusses on parents’ help-seeking about symptoms in children. That research suggests that while seeking diagnosis and treatment is one of the usual reasons for a clinical consultation, it plays a less important role in the motivations of parents

seeking help for children out-of-hours, as they primarily want to rule out risks (Hugenholtz et al. 2009). The authors argue that seeking help in this way can be seen as an expression of the central role of risk regulation in modern society.

In this thesis, I have developed this use of the concept of risk and suggest that it allows for greater understanding of people's uncertainty about the meaning of symptoms and their worry that symptoms could be or become serious. As I have shown, this was a significant feature of many interviewees' accounts of their decision to call NHS 24. For example, Peter interpreted his daughter's earache as a potential sign of meningitis; Natalie interpreted her nosebleed as potentially indicative of high blood pressure or a brain haemorrhage; Heather interpreted the lump on her son's groin as a potential sign of twisted testicles; and Maggie thought that her swollen ankles might signify a wound infection. Others did not have a specific illness in mind, but nevertheless were worried about potential danger such as Katie, whose baby was crying or Andy whose diarrhoea and vomiting lasted for longer than expected. Several people were worried about the side-effects of medications or the possibility of interactions if they took steps to self-care. Others were shocked by something new and unfamiliar that they couldn't interpret, such as the swelling on Doreen's hand or the lump on Lauren's abdomen. Although people did not themselves use the word risk and most claimed that information about risk doesn't affect them, they did talk about 'danger' and risk discourses shaped many of their accounts. This suggests that people are aware of threats, for example from particular diseases (such as meningitis), drug interactions and microbial resistance. These sorts of worries may not be articulated during the NHS 24 call (Barry et al. 2000) and their absence in accounts of people's own help-seeking could be explained by the fact that 'hypochondriac' is a label that people are keen to avoid.

A sense of risk and uncertainty about the meaning of symptoms explains the importance of reassurance in these accounts. Reassurance has been noted as an important feature of clinical consultations in previous research (Cunningham-Burley and Maclean 1991; Donovan and Blake 2000), including in the context of NHS Direct (O'Cathain et al. 2000; Rubin et al. 2010). A finding of my study which has not been emphasised in much of the previous literature on help-seeking is that

reassurance is not just an important *outcome* of calls to NHS 24, but that seeking reassurance was given by many participants as a key *reason for calling* the service. As in Hugenholtz et al.'s (2009) research, people were not necessarily looking for treatment or appointments, but were calling NHS 24 as a way of assessing and managing risk and checking that they were 'doing the right thing'. Those who did not experience calling NHS 24 as reassuring, such as James and Robert, already had a clear idea of what was causing their pain and the outcome they wanted, which was to be seen face-to-face.

This research also adds an understanding of *how* calls to NHS 24 are experienced as reassuring. Although some people find extensive questioning in order to rule out serious illness frustrating, in chapter 5 I described how many participants in this study experienced it as reassuring, particularly if they were asked what they perceived to be 'sensible' or the 'right' questions. In calls to NHS 24, the absence of visibility (Pettinari and Jessop 2001) means that the focus is (of necessity) on the patient's description of their symptoms rather than on the use of diagnostic technologies or tests. Leder (1990) describes 3 types of 'texts' that are constituted and interpreted in the clinical encounter. These are the 'narrative text' which is established during history-taking; the 'physical text' of the patient's body and the 'instrumental text' which is constructed by diagnostic technologies. In calls to NHS 24, advisers must rely only on the narrative text, which Leder describes as the most collaborative as it involves the patient in interpretation and arriving at shared meaning. In the absence of physical and instrumental texts, the caller's narrative takes on additional significance which it may not have if the clinician examining them was oriented to a stethoscope, thermometer or to the patient's body. This is likely to contribute to the way that callers were reassured by feeling listened to, not having their worries dismissed and not being made to feel that they were wasting somebody's time. There was also an important and new finding in this research about the way that people experience being provided with a worsening statement as not just reassuring, but as legitimisation of their decision to seek help, confirmation that they have 'done the right thing' and, for some, encouragement to contact the service again should they experience similar symptoms in the future. These findings are congruent

with those of Rubin et al. (2010) on how NHS Direct is experienced as reassuring, but add detail in terms of the importance of the call structure.

There is room for further development of the concept of risk in the context of interpretation of acute symptoms and decisions about seeking help. The idea expressed by Hugenholtz et al. (2009) that seeking help from the professional sector is a rational response to symptoms in the 'risk society' has implications for how we understand the use of health services for seemingly 'minor' symptoms. The importance of reassurance is significant in terms of the role of NHS 24, as calling presents a way for people to manage risk and uncertainty. This helps us to understand why feeling worried and needing reassurance may be considered by callers as sufficient justification for seeking help (Adamson et al. 2009).

8.3.2 Responsibility

In this thesis I have engaged with two connected but sometimes incompatible conceptualisations of responsibility. The first is individual responsibility or 'active citizenship' in a neoliberal society (Petersen and Lupton 1996) as constructed in discourses about the appropriate use of health services. The second is responsible patienthood or parenthood as constructed in risk discourses which emphasise the importance of 'getting things checked out' and not taking chances with health, especially that of children. These conceptualisations are connected in that both are concerned with appropriate conduct and 'doing the right thing' in a given situation. I suggest that they are sometimes incompatible as the demands of responsible citizenship to avoid the unnecessary use of health services may conflict with the imperative not to take risks with health.

In chapter 2, I outlined the links between the promotion of self-care and a shift in policy rhetoric towards greater emphasis on individual responsibility, which I suggested was an important policy driver for the establishment of NHS 24. These themes have been addressed in the literature on NHS Direct, with a focus on what the introduction of new technologies of care means for notions of citizenship and empowerment. That research, building on previous work problematising ideas of 'empowerment' (Anderson 1996; Chapple and Rogers 1999), highlights that people

may wish to ‘take responsibility’ in some circumstances but not in others, and that sometimes ‘empowering’ people may involve enabling and legitimising their access to services (O’Cathain et al. 2005). Lupton (1997) discusses the ambiguity in people’s accounts of the extent to which they wish to be responsible for health care decisions and suggests that people can take on both an active consumer and passive patient role at different times, or even simultaneously, although this can generate tensions ‘in a sociocultural context in which autonomy and rationality are highly privileged and dependency upon others is largely viewed as evidence of weakness and irrationality’ (1997: 380). Such tensions are visible in the accounts of participants in this study and I have highlighted the ways in which complex and contradictory accounts illustrate the difficulty people face in negotiating and reconciling these conflicting types of responsibility and in presenting themselves as both responsible citizens and responsible patients or parents.

Most of the participants in this study fit with the idea of the active citizen, as they monitor their health and that of the people they care for and react to symptoms, drawing on a variety of sources of information, making decisions and managing risks. However, this self-surveillance may, paradoxically, lead to increased awareness of problems which come to be interpreted as symptoms, thus leading to increased service use as the result of a need for both legitimation and reassurance (Goode et al. 2004a; Goode and Greatbatch 2005). At the same time, many participants constructed themselves as responsible patients or parents who would seek expert advice in order to assess and mitigate potential risks. They did this by presenting justification for their own use of services, highlighting the chronicity, severity or unfamiliarity of symptoms. The importance of seeking help was reinforced by ‘past frights’ when they hadn’t consulted quickly enough and by occasions when they were chastised by professionals for waiting too long. Although calling NHS 24 about symptoms that are not obviously urgent may be seen as abdicating responsibility for health and a manifestation of the ‘nanny state’, as suggested by some focus group participants, these accounts show that it can also be understood as part of how individuals take responsibility for themselves or the people they are caring for.

In responsible decision-making, the impact of help-seeking on scarce health service time and resources must be offset against the much greater potential costs, to the individual and to the tax payer, of developing a serious illness. Therefore, when a decision is made to seek help, the responsible service user must ensure that they seek help in the right place, at the right time. The issue of appropriate use arises in particular in relation to those services that the public can access freely of their own accord (Rogers et al. 1999), such as primary care, emergency departments, ambulances and telephone helplines, including NHS 24. However, what is appropriate has not been adequately defined in the context of any of these services and ideas of appropriateness differ between lay people and professionals (Sanders 2000) and between different groups of professionals (Cook et al. 2010). As noted in section 8.2 above, this thesis has shown that appropriateness in relation to calling NHS 24 is contingent on what the service is understood to be for. Ambiguity around the purpose of NHS 24 allows room for the flexible construction of appropriateness on the part of both staff and callers. Interviewees constructed their responsibility in this sense by showing awareness of the pressures on the health care system and drawing on discourses of resource use and not wanting to waste anyone's time.

The data related to responsibility must be considered in light of the discussion in the previous section about risk, as risk assessment is one factor that underpins considerations of appropriate action when dealing with symptoms and illness. This has been previously highlighted by Houston and Pickering (2000: 237) whose participants felt a strong sense of responsibility for their children's health; however, 'when faced with a sick child the sense of responsibility was often eclipsed by fear of the potential consequences of the child's illness or of "making the wrong decision"'. This thesis adds to our understanding of the ways in which seeking help can be seen as taking responsibility, particularly in cases of risk or uncertainty and particularly when an individual does not feel they have the knowledge or skills to interpret or manage a situation by themselves.

8.3.3 Knowledge and expertise

Knowledge about symptoms and treatment is a key factor that influences the decision to seek help or to self-care; even quite serious illness can be managed in the popular sector if its meaning and how to deal with it is understood (Hopton et al. 1996; Cantrill et al. 2006). In chapter 7, I described how people draw on a broad range of knowledge including that gained directly from professionals, their own experiential or embodied knowledge, socially derived knowledge and ‘common sense’ when interpreting symptoms and deciding what to do about them. There is a ‘public hierarchy of authority in relation to health matters’ (Cornwell 1984: 118) and professional expertise is likely to be seen as more legitimate than popular expertise (Stevenson et al. 2003), even though the difference between the explanatory models used by lay people and professionals in Western societies has legitimately been questioned, as lay people’s understandings and experiences are almost certainly influenced by expert knowledge systems (Shaw 2002). Both lay people and experts draw on a combination of theoretical and practical knowledge and translate it to be useful in particular situations (Pols 2012), seeking advice from others when they are unsure about something or reach the limits of their expertise (Roberts 1992). The way in which different forms of knowledge are made sense of and manipulated in practices of self-care has been described by Dew et al. (2014) in terms of ‘hybridity’ as people take ideas from different sources and adapt them according to their own interests and understandings.

My findings emphasise the range of sources of knowledge that people draw on, but unlike the participants in Dew et al.’s (2014) study, there was little evidence here of explicit rejection of biomedical expertise. Instead, professional knowledge was privileged and lay knowledge was presented by most, though not all, participants as less trustworthy. In this regard, it is important to highlight again the difference between acute, self-limiting symptoms (which may nonetheless be serious) and chronic illnesses. A number of interviewees are ‘expert’ in the management of their long-term conditions (e.g. Grant and his MS or Grace and her arthritis) and have undertaken extensive research, drawing on knowledge from the popular, professional and folk sectors and developing personalised illness management strategies which

are ‘hybrids’ of different practices, as described by Dew et al. (2014). However, acute illnesses and injuries don’t fall within the realm of this expertise. The concept of the ‘expert patient’ (Department of Health 2001) is most relevant when applied to people with long term conditions and is arguably less relevant to discussions of minor illnesses, which are so numerous, varied and short-lived that people are unlikely to want or need to become ‘experts’ in them, although they may have the ‘know-now’ (Pols 2012) to deal with them as long as they are familiar and unthreatening. Indeed, Dew et al. (2014) acknowledge that the findings of their research into self-medication practices are less likely to be applicable in relation to acute conditions.

The participants in this study are engaged in on-going practices of self-care, but recognise the limits to their own knowledge and feel it is important to have access to professionals once they reach a point where they are no longer confident that they know what to do. This echoes the finding of Kielmann et al. (2010) that, in order to self-care, people need flexible and responsive access to support from professionals and reassurance that they are doing the right thing. Many of the participants in Kielmann et al.’s study felt that they had good knowledge of their own bodies and their conditions, but some ‘emphasised the limits of their knowledge’ (2010: 59) and when they felt they had reached the limit of their capacity for self-care, they expressed a need for expert advice. The findings of my study in relation to knowledge are complex and sometimes contradictory as people navigate between constructing themselves as knowledgeable while also highlighting the limits to their knowledge. They describe how they seek and use lay knowledge in their decision-making but construct themselves as distrustful of it; and they describe how they regularly manage symptoms and engage in practices of self-care but privilege professional knowledge over their own. At the same time as people tell stories which show themselves as having considerable knowledge about their own health and that of their children, many are careful to add the caveat that they are ‘not an expert’, which suggests that claiming this knowledge is somewhat problematic. These complexities and contradictions are interesting and are interlinked with the difficulties of constructing a responsible self.

It has been suggested that, in the risk society, people engage reflexively with expert advice and are more willing to question and challenge it, even as they become ever more reliant on it (Giddens 1991). Research on NHS Direct considered the extent to which callers engage reflexively with expertise and suggested that theories of reflexive modernisation are inadequate to explain the way that people use knowledge in making decisions about help-seeking (Hanlon et al. 2003; Goode et al. 2004a; Greatbatch et al. 2005). That research suggests that people engage with their health in a complex manner; they are ‘traditional’ in their use of expertise but are also ‘sceptical of and active in their engagement with the NHS’ (Hanlon et al. 2003). Goode et al. (2004a: 218) found ‘little evidence of a crisis of legitimacy as far as medical expertise per se was concerned’ and suggested that the need to draw on expertise in order to interpret the meaning of symptoms leads to ‘more rather than less reliance on experts’ (2004a: 228). Although people do reflexively engage with and critique expertise, interpreting it in the light of their own experiential and embodied knowledge (Dew et al. 2014), the extent to which trust has actually been undermined in the context of late modernity is called into question by the research on NHS Direct (Hanlon et al. 2003; Goode et al. 2004a; Greatbatch et al. 2005). People use information and technology to supplement or enhance consultations with professionals, but ultimately they trust what they are told by professionals more than information sourced elsewhere (Lupton 1997; Nettleton and Hanlon 2006). My findings fit with those related to NHS Direct in that some of the callers I interviewed expressed a willingness to challenge professionals in their accounts of use of other health services but rarely questioned the advice they were given by NHS 24 and certainly showed little evidence of distrust. Again, I suggest that this is likely to be because of people’s lack of expertise in dealing with acute and unfamiliar symptoms, in comparison to long-term illnesses about which they may have developed considerable knowledge of their own.

In spite of ever-increasing access to education and knowledge, demand for health services, including NHS 24, continues to rise. My findings suggest that this is due to the importance of not just expertise, but expertise embodied in the symbolic category of the ‘professional’. This is linked to the ways in which reassurance is enacted, as

people value the interactional aspects of consultation, being asked the ‘right’ questions and receiving advice which is personalised to their individual situation. I suggest that increased access to professional knowledge, rather than decreased access to lay knowledge, accounts for increasing demand for formal health services.

8.4 Implications for policy and practice

In this thesis I have argued that the proliferation of routes to health care in Scotland may increase choice for patients but may also increase complexity and therefore confusion and anxiety about help-seeking. I have drawn on the example of the ‘Know Who To Turn To’ campaign to demonstrate how services increasingly require people to categorise their symptoms, according to urgency, in order to seek help appropriately. However, the idea of ‘appropriate’ service use suggests that the ‘assignment of meaning is completely unproblematic’, so that everyone, in every situation, knows the right interpretation and the right thing to do (Dingwall 1976: viii). In fact, what is considered to be appropriate or inappropriate is socially constructed in particular contexts and generally serves the purpose of reinforcing normative behaviours. In the case of the use of health services, this is linked to both professional prestige, the management of demand and expectations about who should use particular services and when.

Dixon-Woods et al. (2005: 53) suggest that ‘many services rely on implicit assumptions about the “ideal user” – someone who uses services precisely in the way they are intended for precisely the problems providers have identified the services as serving’. However, not only do different services have different ideal users, but different professionals within services may have different ideas about who their ideal users are. In addition, ideal use may vary according to the time of day or night as is the case with NHS 24 or according to the time of year as people are exhorted not to use hospitals during the ‘winter crisis’ when services are under additional pressure. Although NHS 24 is, in theory, designed as a single point of contact which should make help-seeking easier, restricting its use, in the out-of-hours period, to situations which are considered to be urgent means that people must determine when it is appropriate to call NHS 24. I have suggested in this thesis that the representation of

NHS 24 as being for ‘urgent’ care poses problems for callers who struggle to interpret the urgency of symptoms, something which is often only possible in retrospect (Roberts 1992). This has implications in terms of access to services and the messages that are conveyed to the public.

Although interpretation of symptoms is a dynamic process, appropriate service use depends on correctly categorising symptoms, at the point of help-seeking, as ‘minor’, ‘urgent’ or ‘emergency’. However, these categories have been shown to be highly subjective and may be differently understood by lay people and by professionals, as well as by different individuals within these groups. An individual’s assessment of the urgency of their need for help may not always correspond to ‘official versions of what constitutes appropriate demand’ (Goode et al. 2004a: 223). While some people who call NHS 24 may know what their symptoms mean, in many cases they may not be able to engage in the interpretive work required to determine the right thing to do. The rationale for NHS 24’s move away from the idea that people can call ‘virtually at any time, day or night, and for almost any reason’ (NHS 24 Independent Review Team 2005a: 9) has been well documented, but perhaps there is a need to reconsider what it means to be a ‘gateway to the NHS’. The sort of flexible and responsive access to professionals that is advocated by Kielmann et al. (2010) as necessary to enable people to self-care is, in theory, exactly what NHS 24 is able to provide. However, by conveying the message that the service is for urgent care only, people who just need some support for decision-making or reassurance that they are doing the right thing may be deterred from seeking help.

This research adds to the already extensive body of literature critiquing the idea that it is effective to ‘educate’ people about the appropriate use of health services (Roberts 1992; Hopton et al. 1996; Milewa et al. 2000; Heaney et al. 2001; Little et al. 2001; Dixon-Woods et al. 2005; Cornally and McCarthy 2011) and suggesting instead that services should be developed in a way that meets the needs of those who use them (Snooks et al. 1998; Chew-Graham et al. 2004; Bezzina et al. 2005). My findings support the idea that the premises on which educational interventions are based do not take adequate account of the social processes and structural constraints that shape help-seeking decisions. Yet calls for more ‘education’ about appropriate

service use continue to be made, as demonstrated by the British Medical Association who recently carried a motion to call on governments to:

develop a requirement for all schools to introduce a new element to their curricula which educates young people across the UK in the appropriate, safe and effective use of health services, and raises awareness about responsibility for self-management of health when required (BMA 2014: 8).

This type of call reinforces the idea that pressures on health services are the result of the inappropriate behaviour of patients and demonstrates the continued popularity of the ‘information deficit model’ (Heaney et al. 2001). It also shows how a new sort of relationship with health services is being demanded from citizens as they must take responsibility not only for their own health, but for the overall effectiveness of the health system (Scottish Executive 2005a). In terms of the development of out-of-hours care, rather than focussing on ensuring that lay people develop an understanding of medical urgency and appropriateness which conforms to that of health professionals and service providers, it should be considered whether current models of provision best meet the needs of service users.

The policy emphasis on increasing the use of self-care needs to take account of the fact that most decisions to seek help about minor ailments are evaluated and rational (Cantrill et al. 2006). If people feel that their help-seeking is being judged as ‘moral inadequacy’ it creates anxiety, whereas if they don’t feel criticised they are more likely to experience positive regard and subsequently increased self-esteem and self-efficacy (Neill et al. 2013). The findings of this research with regards to reassurance are significant and suggest that there is potential to build on the capacity of NHS 24 to reassure; however, there are signs that, as predicted by Goode et al. (2004a), increasing demand may threaten this capacity (Puttick 2015). Increased pressure on the service may exacerbate those aspects of NHS 24’s provision that have the potential to increase anxiety for some people, most notably the use of call-back (Richards et al. 2007). This may be less distressing in cases where people understand that calls are prioritised by urgency and that the reason they are being kept waiting is because they are not considered to be in danger. Therefore, if the use of call-back

cannot be eliminated, there may be benefit in making the prioritisation process more overt and letting people know that the queue is monitored by a clinician.

This research also has implications for the increasing emphasis on provision of self-care information online. Although there is some evidence that use of the NHS Choices website reduces use of primary care for young, healthy people (Murray et al. 2011), the present study highlights again the need to be mindful of the digital divide and the unsuitability of online information in situations where people need reassurance. In such cases, my findings emphasise the importance of embodied knowledge, expressed as the need to ‘speak to somebody’ who can ask the ‘right’ questions and provide advice personalised to the individual. My research suggests that searching for information online is only considered to be suitable for symptoms which are definitely not considered serious, or in cases where people already have a diagnosis that they want to learn more about; internet use seems to be considered unsuitable for the types of acute symptoms that participants in this study were seeking help about.

Over the course of its existence, NHS 24 has changed in response to policy imperatives and the needs of its stakeholders, including callers. Much of this change has been about attempting to manage and reduce demand, but the continued increase in calls to the service suggests there is a need to reconsider how NHS 24 might be influencing demand in unintended ways. Illness behaviour is also changing; less tolerance of uncertainty and the importance of ‘professional’ advice in managing risk means that demand is likely to continue to grow. The findings of this research provide NHS 24, for the first time, with an insight into how the organisation is understood. Both staff and callers have differing and flexible understandings of NHS 24 and its role within the health care system. For staff, this allows room for negotiation around the legitimacy of claims to care when people are able to construct themselves as deserving. However, this flexibility also allows those who fail in this identity work to be criticised for using the service inappropriately. For callers, there may be some anxiety around seeking help if they feel that their symptoms are not ‘urgent’ but they are nevertheless worried and feel a need for advice. The

organisation should perhaps consider the possible repercussions of the way it has positioned itself, or been positioned, as an urgent care or even ‘emergency’ service.

8.5 Implications for further research

There has been a recent emphasis in medical sociology on chronic illnesses, reflecting changing priorities within the field and wider society. My research suggests that there is perhaps a need for new thinking, as well as a return to old thinking, about minor illnesses. My findings confirm the enduring relevance of many classic studies of ‘everyday’ illness (Locker 1981; Blaxter and Paterson 1982; Cornwell 1984; Cunningham-Burley 1990) but suggest a need to develop theories about how people deal with acute symptoms in the context of the ‘risk society’. This also creates space for a new conceptualisation of risk which encompasses the sense in which it is used in this thesis.

There is room for further sociological work on the concept of reassurance. In particular my research raises interesting questions about how reassurance is enacted through organisational procedures and the work that reassurance is doing in bridging the popular and professional sectors of health care.

There is a need for more in-depth consideration, from a sociological perspective, of campaigns like ‘Know Who To Turn To’ and discourses of appropriate help-seeking. Although the attribution of moral judgements to help-seeking is by no means new, I suggest that the way in which the responsibility for the effectiveness of health services is being pushed on to individuals *is* new. While this is unlikely to change illness behaviour, as most people think that it is only ‘other people’ who use health services inappropriately, it may lead to both the demonisation of those who are seen to be ‘time-wasters’ and to increased anxiety for patients in making decisions about symptoms.

This study has been the first to examine understandings of NHS 24 and how it may be conceptualised within the broader health care system. I have suggested that it raises interesting issues about the boundaries between the popular and professional sectors and between ‘self-care’ and ‘help-seeking’. Although the importance of

‘boundary work’ for professionals in clinical call centres has been discussed previously (Goode and Greatbatch 2005), this research suggests that there are other types of boundaries that are maintained, traversed and negotiated by NHS 24. The concept of the ‘boundary object’ (Star and Griesemer 1989) has previously been applied to organisations (Moore 1996; Guston 1999); however, there may be room for further theoretical development of the concept of the ‘boundary organisation’ to explore whether or not this might be a useful way of understanding NHS 24 and the flexibility with which people engage with it.

8.6 Final reflections

This thesis has drawn on both established and new concepts in order to make sense of the ways that people understand and use NHS 24, highlighting elements of both continuity and change in illness and help-seeking behaviour (Nettleton and Hanlon 2006). I have been struck by the continued relevance of much that has gone before and the opportunities that newer ideas and concepts offer for understanding new forms of health care provision.

There is more change ahead for out-of-hours primary care in Scotland, as the Scottish Government has recently announced a review (Scottish Government 2015) although details are not yet available. There may be opportunities for NHS 24 to build on its strengths and its flexibility in further adapting to changing needs.

However, much of the success of any new model of care will depend on the extent to which services are designed to meet the needs and expectations of the public, rather than relying on attempts to educate people to become ‘ideal users’ and to fit with the expectations of services.

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Appendices

Appendix 1: Pilot study- Focus group topic guide

Introduction 5mins

- Introduce the study, its aims and the researcher
- Discuss ethical issues- confidentiality, anonymity and recording

Context – identifying what is meant by minor illness 5-10mins

- Explore what sorts of things participants identify as minor illnesses (brainstorming)

Illness behaviour 10mins

- Explore what is considered to be appropriate action/ reasonable behaviour in the event of the sorts of illnesses identified above (what would you do?; what do you think others do?)
- What sort of symptoms lead to action of any kind?
- Explore self-care/ self-medication, coping strategies, help seeking, support and advice (what would you do?; what do you think others do?)

Caregiving 10mins

- If participants have a caring role explore how they make decisions about symptoms in those they care for and how they look after them
- How does this differ from how they look after themselves? (what do you do?; what do others do?)

Calling NHS 24 10mins

- Explore people's general feelings and views about using NHS 24
- Explore ideas about using an out of hours service rather than seeking help during working hours
- Would a decision to seek help out of hours be more likely to be due to symptomatic reasons or social reasons?

Conclusion 5-10mins

- Participants' general views on the study and what should be priorities for research

Appendix 2: Focus group participant information sheets

Non-staff groups

About the research

NHS 24 is a 24-hour nurse-led helpline which provides health assessment, advice and where necessary, referral to other services. 'Calling NHS 24' is a study about the reasons why people decide to call NHS 24, particularly for minor illnesses, and how it is changing how people use health services.

I am interested in hearing about what people do when they are ill and how they decide when to seek advice about symptoms. If you are a parent or carer I would like to hear about how you make decisions about symptoms in the person you care for. I would also like to find out about how people use health services, especially in the evenings and at weekends. This may include NHS 24, but you don't have to have used NHS 24 before to take part in the study.

About the researcher

My name is Emma Doyle and I am a student from the Centre for Population Health Sciences at the University of Edinburgh. This study is for my PhD project. It is funded by the Economic and Social Research Council and NHS 24 and is being supervised by Prof. Sarah Cunningham-Burley.

Your participation

I would like to invite you to take part in a small group discussion on the themes mentioned above. This will last for about an hour, at a time and place to be agreed. The discussion will be quite informal and refreshments will be provided.

It is entirely up to you whether or not to take part in this study. Even if you agree to take part you can still change your mind at any time. If you do come along to the group, you will not have to answer any questions that you don't want to answer.

You will be asked to sign the attached form to show that you have read and understood this information and have voluntarily agreed to take part in the study.

Confidentiality and anonymity

The discussion will be audio-recorded. This is so that I have an accurate record of what is said. However complete confidentiality and anonymity is guaranteed. What is said in the group may be used in reports or papers to do with my study but no real names will ever be used and it will not be possible for others to identify you.

For further information

If you have any questions at all about this study, or if you need to know more before deciding to take part, please don't hesitate to contact me.

Phone: [number provided]

Email: e.a.doyle@sms.ed.ac.uk

Staff groups

About the research

'Calling NHS 24' is a study about the reasons why people decide to call NHS 24, particularly for minor illnesses, and how it is changing how people use health services.

I am interested in hearing from staff about your perceptions of why people call, particularly with minor symptoms, and how you believe people decide when to seek advice about symptoms in themselves or in those they care for. I would also like to find out if you think that the introduction of NHS 24 has changed how people use health services and, if so, in what ways.

About the researcher

My name is Emma Doyle and I am a student from the Centre for Population Health Sciences at the University of Edinburgh. This study is for my PhD project. It is funded by the Economic and Social Research Council and NHS 24 and is being supervised by Prof. Sarah Cunningham-Burley.

Your participation

I would like to invite you to take part in a small group discussion on the themes mentioned above. This will last for about an hour, at a time and place to be agreed. It will be either during your working hours or you will be given time in lieu if you come in early/ stay late (this is at the discretion of your line manager). The discussion will be quite informal and refreshments will be provided.

It is entirely up to you whether or not to take part in this study. Even if you agree to take part you can still change your mind at any time. If you do come along to the group, you will not have to answer any questions that you don't want to answer.

You will be asked to sign the attached form to show that you have read and understood this information and have voluntarily agreed to take part in the study.

Confidentiality and anonymity

The discussion will be audio-recorded. This is so that I have an accurate record of what is said. However complete confidentiality and anonymity is guaranteed. What is said in the group may be used in reports or papers to do with my study but no real names will ever be used and it will not be possible for others to identify you.

For further information

If you have any questions at all about this study, or if you need to know more before deciding to take part, please don't hesitate to contact me.

Phone: [number provided]

Email: e.a.doyle@sms.ed.ac.uk

Appendix 3: Focus group consent Form

Calling NHS 24: An exploration of illness behaviour among patients using the service

Please only sign this consent form if you have decided to take part in the study. By signing this form you are agreeing with the following statements:

- I have voluntarily agreed to take part in a discussion group as part of this study
- I understand that I can change my mind and withdraw at any time
- I have read and understood the Participant Information Sheet
- I have been given enough information and have had the opportunity to ask questions
- I understand that the discussion will be audio-recorded but my participation will be anonymous and any views I express will be treated in confidence

Participant's Name (Printed):

Participant's signature:

Date:

Thank you for agreeing to take part in this study, your contribution is very much appreciated.

Appendix 4: Interview schedule

Introduction

- Introduce the study, its aims and the researcher
- Discuss ethical issues- confidentiality, anonymity and recording
- Obtain informed consent to continue and to record

Background

- Ask for a little bit of information about the person eg family / household circumstances, who they live with, if they are a parent or carer, if they work outside the home, general support network (eg extended family, friends nearby?)
- If there are dependents, who does the caring?

Calling NHS 24- Most recent call

- Explore most recent call- what had been happening before call (self-care used / lay support sought) and what made them decide to call (reasons primarily symptomatic or social? What were the triggers?)
- What were their expectations going in to the call?
- What was the outcome of the call and how did they feel about it?
- Were their expectations met?
- What did they do afterwards? (eg followed advice as given/ ignored advice/ sought another opinion- explore reasons)
- Explore why they called out of hours rather than during working hours? (Could call have waited and if so why didn't they wait?)
- What might they have done if NHS 24 wasn't available?
- Have they experienced a similar episode of illness in the past? Did they call NHS 24 then? If not, why not/ what was different about that time?
- If they (or someone they care for) experienced similar symptoms in the future, would they call again or would they do something different given what happened last time?

Calling NHS 24- More generally

- What does the term 'NHS 24' mean to the person? / What do they think it's for?
- Do they always call NHS 24 when feeling unwell (or caring for someone who is unwell)? If not, what sort of things might they do instead?
- Who usually calls?
- If they have used NHS 24 on more than one occasion do they usually use it in hours or out-of hours?
- Have they used the online service? (Explore opinions on that)
- Have they experienced a similar episode of illness when they didn't call NHS 24? If so, what was different about that time?
- Explore what they think about the relationship between NHS 24 and their own GP or other primary care services
- What ways might NHS 24 be improved?

Caregiving

- Discuss caring roles if appropriate eg children /older relative/ neighbour
- If a parent or carer- talk about how they determine illness in the person or people they care for and how they look after them. How does this differ from how they determine illness in themselves or look after themselves?
- Who usually does the caring in the household? Who decided to call NHS 24?

Broader context of illness behaviour

- Explore memories of being ill as a child or in the past, eg were they often ill, who looked after them, how were they looked after? (Explore family practices regarding illness behaviour e.g. use of home remedies, over the counter medicines, call the doctor, visit GP / hospital etc)
- Explore if the person is often unwell (eg in recent months/ years)
- What sorts of illnesses? (eg chronic, recurring, minor)
- What do they usually do when they are unwell? (Explore self-care/ self-medication, coping strategies, help seeking, support etc)
- Is this similar to what they think others (family/ friends /peers) would do in a similar situation? (Explore how current behaviour differs from illness behaviour identified in childhood or in others)
- Do they think that certain groups of people use health services more than others? (Who? What are the differences?)
- What do they consider to be appropriate or responsible use of health services?

Appendix 5: NHS REC favourable opinion letter

All supporting documentation referred to is available on request

Lothian NHS Board

South East Scotland Research
Ethics Committee 01
Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone 0131 536 9000
Fax 0131 536 9088



Enquiries to Sandra Wyllie
Extension 35679
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Sandra.Wyllie@nhslothian.scot.nhs.uk

20 March 2012

Ms Emma Doyle
PhD Student
CRFR 24 Buccleuch Place
University of Edinburgh
Edinburgh
EH8 9LN

Dear Ms Doyle

Study title: Calling NHS 24: an exploration of illness behaviour
amongst people using the service
REC reference: 12/SS/0035

Thank you for your letter of 20 March 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).



Headquarters
Waverley Gate, 2-4 Waterloo Place, Edinburgh EH1 3EG

Chair Dr Charles J Winstanley
Chief Executive Professor James J Barbour O.B.E.
Lothian NHS Board is the common name of Lothian Health Board

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Response to Request for Further Information		20 March 2012
REC application		21 February 2012
Interview topic guide	Version 1	08 February 2012
Participant Questionnaire and Consent	Version 1	08 February 2012
Participant Consent Form	Version 1	08 February 2012
Cover Letter participants	Version 1	08 February 2012
Calling NHS 24 - Participant Information Leaflet	Version 2	15 March 2012
Calling NHS 24 - Recruitment Instructions for NHS 24 Staff	Version 2	15 March 2012
Protocol	Version 1	20 February 2012
Summary/Synopsis	Version 1	20 February 2012
CV - Emma Doyle		08 February 2012
CV - Sarah Cunningham-Burley		14 February 2012

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/SS/0035	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Yours sincerely



Dr Janet Andrews
Chair

Appendix 6: Recruitment instructions for NHS 24 staff

Information for staff involved in recruitment of participants

About the research

'Calling NHS 24' is a study about the reasons why people decide to call NHS 24, particularly for minor illness or injury in themselves or others, and how it may be changing how people use health services. It involves interviewing people who have called NHS 24 shortly after their call. A range of people from across Scotland will be invited to take part.

About the researcher

Emma Doyle is a student from the Centre for Population Health Sciences at the University of Edinburgh. This study is for her PhD project. It is funded by the Economic and Social Research Council and NHS 24 and is being supervised by Prof Sarah Cunningham-Burley, Prof Brian McKinstry and Dr John McAnaw.

Recruitment of participants

With the kind agreement of management at NHS 24, it has been decided to ask frontline staff to assist with the recruitment of participants to the study. If you have been given this information sheet, it is because you are requested to assist. This will involve asking specific callers for consent to send them further information about the study. You will only be asked to do this on a small number of occasions over the coming 6-9 months.

What to do

The instructions on the reverse of this sheet tell you which callers should be asked for consent to be contacted. You do not need to give the callers any information about the study or enter into any discussion with them about it. You are asking them for consent to use their **name, address and phone number only**, no other information, and they will be sent an information leaflet which will answer any questions they may have. They may receive a follow up phone call after they are sent the information. They will be under no obligation to do anything or to have any further involvement once they have received the information.

If a caller consents to be contacted please make a note of the **caller's** name, address and phone number on the form provided and return it to a team leader at the end of the shift.

NB- The request is for the contact details of the CALLER not the patient if it is a third-party call.

Thank you very much for your assistance with this process. Staff will be kept up to date with the progress of the study through the Insight magazine. If you have any questions you can contact Emma on e.a.doyle@sms.ed.ac.uk.

Who to ask

Please ask all callers who are calling for themselves or on behalf of someone else in cases where the patient has **an illness or injury** and where the outcome is **self-care advice/ non-referred/ routine GP**.

Please do not ask

- Callers who are under 16
- Callers who may lack the capacity to give informed consent (eg if the caller seems confused or if the call is mental health related)
- Callers who, in your opinion, have been distressed during the call
- Anyone else who, in your professional opinion, you feel it would be inappropriate to ask

When to ask

Please ask at the end of the call, after you have given the self-care advice and worsening statement, but before saying goodbye.

What to say

Please use the following script:

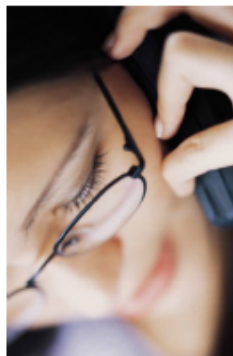
We are carrying out some research with the University of Edinburgh about people's use of NHS 24. The researcher would like to send you some information about the study. You would be under no obligation to take part. Would it be alright with you if we took your name, address and phone number only so that she can contact you about the study?

In order to keep call times down, please don't get into any conversations about the research. If asked, it is fine to say that you don't know anything about it and to repeat that the caller will be sent more information if they are interested. Again, if asked, you can reassure the caller that no information about the call will be passed on and that they are under no obligation to take part. If someone seems uncertain, just reassure them that it is fine to refuse and end the call. For third party calls, please make it clear that it is the name and address of the **caller not the patient** that is required.

Appendix 7: Interview participant information leaflet

Leaflet is designed to be folded

Calling NHS 24: An exploration of people's views about why they use the service for themselves or others



Information leaflet for people who
are being invited to take part in the
study



Version 2: 15/03/12

Who should I speak to if I still have questions?
If you have any questions at all about this research you can contact me:

Emma Doyle
Centre for Research on Families and Relationships
University of Edinburgh
23 Buccleuch Place
Edinburgh, EH8 9LN
e.a.doyle@sms.ed.ac.uk
0757 0891526

or my main supervisor:

Prof Sarah Cunningham-Burley
Centre for Population Health Sciences
University of Edinburgh
Medical School, Teviot Place
Edinburgh, EH8 9AG
sarah.c.burley@ed.ac.uk
0131 650 3217

Is there somebody I can contact with comments or complaints?
If you wish to speak to somebody who is not part of the research team, or to complain about any aspect of this research please contact:

Prof Amanda Amos
Centre for Population Health Sciences
University of Edinburgh
Medical School, Teviot Place
Edinburgh, EH8 9AG
Amanda.Amos@ed.ac.uk
0131 650 3236

Why have I been sent this leaflet?
You have been sent this leaflet because you are being invited to take part in a research study. This leaflet describes the study and explains what would happen if you decided to take part.

You have been chosen because you recently called NHS 24 and during your call you agreed to be sent this information. People from all over Scotland, both male and female and from a range of different age groups, are being asked to take part.

What would I be asked to do?
If you decided to take part I would ask to meet with you to do an interview. This would take 1-1½ hours. It would happen in private at a time and place that suits you. This leaflet explains the process in more detail.

Do I have to take part?
No, it is entirely up to you whether or not to take part in this study. Even if you agree to take part you can still change your mind at any time and withdraw from the study without having to give a reason.

What happens if I don't want to take part?
If you don't want to take part that's absolutely fine. You don't have to do anything and you won't receive any further contact. There will be no record that you were sent this information and your care will not be affected in any way. Thank you for taking the time to read this leaflet.

What is the research about?

NHS 24 is a telephone based service which provides health assessment, advice and where necessary, referral to other services when your GP surgery is closed.

'Calling NHS 24' is a study about the reasons why people decide to call NHS 24, particularly for minor illnesses. I am interested in speaking to people who have called either for themselves or for someone else.

I would like to ask you about your recent call to NHS 24. I am interested in what happened before you made the call, how you felt about the call itself and what happened afterwards.

I am also interested in hearing about what you usually do when you are ill and how you decide when to seek advice about symptoms. If you are a parent or carer I would like to hear about how you make decisions about symptoms in the person you care for.

Who is doing the research?

My name is Emma Doyle and I am a student from the Centre for Population Health Sciences at the University of Edinburgh. This study is for my PhD project. I am being supervised by Prof Sarah Cunningham-Burley and Prof Brian McKinstry from the University of Edinburgh and Dr John McAnaw from NHS 24.

Who is funding the research?

The study is funded by the Economic and Social Research Council and NHS 24.

Are there any risks?

No. There is no known risk if you take part in this study. Your health care will not be affected in any way.

Are there any benefits?

There are no immediate benefits to you but by taking part in this study you would be contributing to research on health services in Scotland. You would have the opportunity to discuss your experiences of using health services and hopefully to influence how NHS 24 and similar services are provided in the future.

Who will see my information?

Any information I have about you and everything you say in the interview will be kept strictly confidential. Your name and address will be kept separately from your interview. I will be the only person who sees this information. When I write up the research I will change your name and any details which might be used to identify you.

What will be done with the results of the study?

The results of this study will be written up in my PhD thesis. I may also use the results in papers for publication or in presentations. I hope that the results will be used to develop the service provided by NHS 24 and other health services. I will send you a summary of the results if you wish.

How will my information be stored?

Your paper questionnaire will be stored in a locked filing cabinet. When the study is finished and written up (no more than 3 years) it will be destroyed. The audio recording of your interview and the typed transcript will be stored on a password protected computer. After the study the audio recordings will be deleted and the transcripts will be archived in anonymised form (this means without any information that could be used to identify you).

What happens next if I decide to take part?

If you decide you are interested in taking part in this study, please complete the short questionnaire and consent form included with this leaflet and send them back, as soon as possible, in the pre-paid envelope provided.

The consent form is to say that you agree for me to contact you. Remember that even if you sign this form you can still change your mind about taking part.

Once I receive your returned form I will

contact you to arrange an interview. This can be at any time suitable for you, including in the evening or at the weekend if you prefer. It can be in your home, or somewhere else that you feel comfortable. You can stop the interview or ask me questions at any time.

Please note that I am not a healthcare worker and I cannot give you any medical advice or opinions. If you have any health concerns you should contact your GP.

Appendix 8: Interview consent form

Calling NHS 24

Consent form

Please read each statement and **initial** the box.

- I confirm that I have read and understood the information leaflet provided for this study. I have had the opportunity to ask questions and have had these answered to my satisfaction ☐
- I understand that my participation in this study is voluntary and that I am free to withdraw at any time without giving a reason ☐
- I agree to take part in an interview as part of this study ☐
- I understand that the interview will be recorded and then transcribed. I understand that no personal data which could be used to identify me will be included ☐
- I understand that the information given in my interview will be used in Emma Doyle's PhD project and may be used by her in other publications, reports and presentations but that I will not be identified ☐
- I understand that the audio recording will be deleted after the end of the study, but that the transcript of the interview may be archived in an anonymised form for use in future research. ☐

Participant's Name (Printed): _____

Participant's signature: _____ Date: _____

Thank you for agreeing to take part in this study, your contribution is very much appreciated.